



HRSA 95-180/180A

Evaluating HIV Case Management

Invited Research & Evaluation Papers

July 1998

HIV/AIDS Bureau

Evaluating HIV Case Management

Invited Research & Evaluation Papers

1998

This publication was funded by the Health Resources and Services Administration, HIV/AIDS Bureau,
Office of Science and Epidemiology under contract with Sociomedical Resource Associates, Inc.

Contract Number: 103HR951164P000-000

Table of Contents

Introduction	1
1. <i>Evaluation of HIV Case Management Services: An Overview</i> by Larry L. Gant PhD CSW	8
2. <i>Research Design Issues in Evaluating the Outcomes of Case Management for Persons with HIV</i> by John A. Fleishman PhD	25
3. <i>Evaluating the Impact of HIV Case Management: Research Issues and Limitations</i> by Susan Elizabeth Lehrman PhD MPH, Daniel Gentry PhD MSHA, and Edward C. Waltz PhD MS	49
4. <i>The Political Economy of HIV Case Management</i> by Martin Nacman DSW	83
5. <i>A Review of Systematic Data Analysis Toward the Effectiveness of H/V Case Management</i> by Jaime L. Amsel PhD, J. Raúl Magaña PhD, and Cécile P. Tran BSc	101
6. <i>Developing Standards of Practice for HIV Case Management: San Francisco's Mode/</i> by Myrna Cozen MPH	125
7. <i>A Cooperative Model of HIV Case Management: Evaluation and Research Issues from Chicago</i> by Paul L. Kuehnert MS RN, Terrie Matthes MA CRADC, and William L. White MA	146
8. <i>HIV Case Management Compared to Other Models of Care Coordination</i> by George E. Sonsel LCSW	161
9. <i>HIV Case Management for Special Populations: the Transition to Managed Care</i> by David P. Ley LCSW	174
10. <i>HIV Case Managers: the Challenge and the Responsibility</i> by Ennes Littrell ACSW	189

Introduction ¹

Case management for people with HIV disease has been widely delivered throughout the United States almost since the disease was first identified. In fact, Federal and non-Federal agencies, including private sector organizations, have focused much of their resources on the service. While case management is neither a new nor unique approach to care coordination, it has received special emphasis in the AIDS epidemic as both an approach and as a distinct service.

Throughout this document, **“HIV disease”** is used to describe the entire spectrum of the natural history of the virus, from post-infection to the clinical definition of AIDS

“HIV case management” refers to case management services delivered to people with HIV disease

In May 1996, Congress enacted Public Law 104-146, the Ryan White Comprehensive AIDS Resources Emergency Act Amendments of 1996. Commonly referred to as the CARE Act, the 1996 legislation reauthorized the original bill, which became law in August 1990. The CARE Act represents the largest dollar investment made by the Federal government specifically for the development of services and service systems for people living with HIV disease. Funds provided through Medicaid and Medicare for HIV care vastly surpass the CARE Act in total dollars on an annual basis. However, the CARE Act helps communities and States address the health care needs of people ineligible for Medicaid or Medicare and provides HIV services not reimbursed by Medicaid or Medicare.

- . Title I directs emergency funding to urban areas (Eligible Metropolitan Areas, or “EMAs”) hardest hit by HIV disease. As of Fiscal Year (FY) 1998, 49 EMAs were eligible for Title I funding.
- . Title II provides formula funding to each State, as well as the District of Columbia, Puerto Rico, and eligible territories to improve the quality, availability, and organization of health and support services for

¹ Matthew McClain, a public health policy and planning consultant in Silver Spring, Maryland, edited this document and wrote the introduction. He was assisted by Wendy Leopold.

individuals and families living with HIV and AIDS. AIDS Drug Assistance Programs (ADAP programs) are funded through Title II.

- Case management is a service eligible for funding through Titles I, II, III, and IV of the CARE Act
- Title III supports outpatient early intervention HIV services for people living with HIV disease in order to reduce the risk of transmission and link people to care that can prevent or delay the onset of symptoms and opportunistic diseases.
 - Title IV supports projects to organize and coordinate a broad range of medical, social, and support services for children, youth, women, and families with HIV disease, and to provide enhanced access to clinical research.
 - Part F supports Special Projects of National Significance (SPNS), AIDS Education and Training Centers (AETCs), and the Dental Reimbursement Program.

While HIV case management has proliferated, it generally has not had a consistent standard for service delivery. Also lacking have been a thorough validation of its aims and purposes, comparative analysis of its multiple forms and models, and research of its various service configurations and outcomes. Despite the absence of such objective findings, case management is often cited by people with HIV disease as a highly needed service. In addition, people who receive HIV case management tend to have high levels of satisfaction with their case manager. Further, studies have shown a correlation between the presence of an HIV case manager and the resolution of problems. Overall, however, health services research data about case management for people with HIV are lacking. This document addresses that gap.

To initiate the project, a group of health services researchers, case managers, and representatives of the Health Resources and Services Administration (HRSA), the Agency for Health Care Policy and Research (AHCPR), and the Health Care Financing Administration (HCFA) met to focus on approaches for evaluating and researching the effectiveness of HIV case **management**.² This document contains edited versions of a series of papers that were commissioned from participants for presentation at the meeting.

² The contractor responsible for convening this meeting and commissioning these papers was Lawrence C. Shulman, ACSW, of Sociomedical Resources, Inc.

The authors invited to contribute these papers represent a broad range of expertise and experiences. Some authors focus their energies on health services research and applied research, while others are program developers and administrators. While each paper offers a unique perspective on its particular topic, most of them offer a description of HIV case management in general and its evolution in the sphere of HIV service delivery. Definitions of case management and HIV-specific case management appear in a number of the articles. The authors also identify research and evaluation issues related to their topic, and many offer recommendations for next steps.

General topics covered by these papers are:

- Evaluation of case management services and designing research on case management
- Cost and how to measure the impact of case management on cost
- Various models of case management
- Case management for specific populations
- Issues related to the case manager's recruitment, training, and education

Papers by Gant and Fleishman begin the series. Gant offers an overview of evaluation of HIV case management, noting that evaluations of HIV case management services have focused on cost-containment. He describes the positive and negative outcomes that evaluations of HIV case management have identified. The next paper, by Fleishman, outlines the methodological problems that will be encountered in designing quantitative research to examine the outcomes of HIV case management. In addition, Fleishman reviews the limited quantitative evidence that has been reported to date, and offers guidance on such matters as experimental and quasi-experimental designs.

The next two papers deal with cost issues. Noting that little has been written on financial cost-benefit and cost-effectiveness of HIV case management (as opposed to cost containment) Lehrman and colleagues discuss issues encountered in evaluating the impact of HIV case management, especially health care cost savings. The paper includes a discussion of specific approaches for assessing the impact of health care costs, including some possible data sources. Nacman's paper offers readers a wide-ranging overview of the development of case management, with an emphasis on

managed care's achievements, problems, and conflicts in relation to HIV case management. The ethical and legal issues that ensue are also discussed.

The next three papers focus on the development and implementation of models of HIV case management. Amsel and colleagues describe nine models of case management and offer two concepts to use when attempting to develop an HIV case management model. These are systematic data collection and the empowerment model. Cozen offers readers an in-depth review of the case management model being developed in San Francisco. The model, which includes the distinct service known as care coordination, aims to build a client-centered, comprehensive, and community-based system of care. Cozen describes key components of the model, as well its standards, outcome measures, and database management system. Kuehnert and colleagues present the regional model of case management that has been developed in Chicago. The model is also client-focused, but emphasizes a collaborative inter-agency structure. Again, evaluation and research issues are provided.

The final group of papers includes two papers focusing on case management for specific populations, and one paper on the case manager. Sonsel compares several different models of case management for specific populations based on the results of three Special Projects of National Significance funded through the CARE Act and administered by HRSA. Ley describes a clinic-based model of HIV case management developed in Chicago for special populations of injecting drug users, affected women and children, and men of color who have sex with men. The model demonstrates how to make use of indigenous case managers and a clinical-case management team approach to better serve these populations. The document ends with an article by Littrell, which charts new ground with a discussion on the education, training, and standards for HIV case management personnel.

During the meeting at which these papers were presented, the group developed a proposed set of outcomes that participants identified during the meeting as essential elements of any evaluation study of HIV case management.

Identifying potential variables and outcomes for use in HIV case management evaluation research at the client level is a challenging undertaking. However, as an initial effort, the meeting participants identified variables as well as outcomes at the client, organizational, and system levels. These are presented in the following tables.

Client level assessment

Any evaluation study of HIV case management should assess at the client level:

1. The amount of time from assessment to case planning to implementation of the care plan.
2. Successful linkage to key services such as entitlements, primary care, housing, mental health services, and immigration assistance.
3. Behavior changes (i.e. risk or harm reduction).
4. Empowerment of clients (which may include self-direction, autonomy, self-efficacy, ability to utilize internal and external resources).
5. Quality of life issues (such as changes in expected trajectories of life for individuals living with HIV disease, reduction in isolation, successful or helpful coping).
6. Improvements in knowledge about HIV disease and the disease process.
7. Resource utilization and appropriate resource utilization (e.g. changes in scheduled versus "crisis" visits and changes in the number of inappropriate emergency room visits).

Organizational-level outcomes

Any evaluation study of HIV case management should assess the following outcomes at the organizational level:

1. Ability to deal with repeated loss of clients.
2. Staff turnover/retention.
3. Levels of burnout.
4. Staff satisfaction

System-level outcomes

Any evaluation study of HIV case management should assess the following outcomes at the system level:

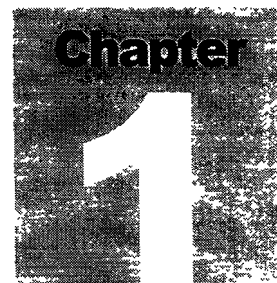
1. Changes in quality and degree of interaction/communication among organizations serving people with HIV and among their staffs (as indicated by case conferences, joint planning, cooperative agreements, sharing of data, organizational merging, achieved economies of scale, shared language and values).
2. Changes, improvements, and/or increases in available service resources (through advocacy by case managers and/or case management organizations or coalitions).

This document should be of use to a wide audience interested in HIV case management, including:

- policy makers
 - Federal and State agency staffs
 - health services researchers
 - evaluators of services, programs, and systems
-

INTRODUCTION

- CARE Act planning councils and consortia
- CARE Act grantees and administrators
- professional and technical personnel of HIV programs
- consumers of services
- advocacy groups
- private organized philanthropy
- educators and trainers.



Evaluation of HIV Case Management Services An Overview

*Larry L. Gant PhD CSW**

HIV case management can be described as the principal service strategy typically provided by a nurse or social worker to persons suffering from HIV disease. This strategy is used to develop the appropriate, comprehensive mix of social, medical, and psychological services needed to maintain the patient in the least restrictive environment and in the most cost-efficient manner (Benjamin, 1988).

Since 1981, case management has been identified as a tool for intervention in HIV-infected populations . The major objectives of HIV case management are threefold: (a) to facilitate the provision of comprehensive, cost-effective health and supportive services to people with HIV disease; (b) to establish services based upon a model (e.g. the San Francisco model) of coordinated, comprehensive health care; and (c) to demonstrate that care can be provided humanely and with cost-effectiveness (Silverman, 1993). Guidelines for the use of case management in both early- and late-stage HIV infection have been comprehensively documented, as have been the calls for rigorous evaluation of same (e.g., Shulman and Mantell, 1988; Mantell and Shulman, 1989; Shulman et al., 1993; elSadr et al., 1994).

Although the case management concept was widely accepted, evidence of its cost and effectiveness was not examined until approximately 1988. Then and now, case management generally was favored as the best method for maximizing the effectiveness of existing services, given the realities of cost

*Dr. Gant is an associate professor at the University of Michigan School of Social Work.

shifting from Federal to State and local governments and cost containment of services for persons living with HIV disease.

Case management has been shown to be a cost effective tool in reducing general per patient expenditures in meeting patient needs and allowing the patient to be an active and informed decision maker in identifying and implementing a specific plan of care. Subsequent studies indicated that case management was effective in linking clients with programs and services, yet it was at a high cost and without obvious gains in the patient's quality of life. Since then, additional research on case management as a means to provide services to persons living with HIV has raised important questions as to case management's ability to reduce inpatient hospital utilization or reduce associated costs.

The final conclusions about the effectiveness of HIV case management await more decisive evidence. The expectations of HIV case management programs have been the demonstration of reducing costs related to care and treatment of people with HIV disease, and providing replicable models designed for community-level HIV intervention. Evaluations of HIV case management services have tended to focus on cost-containment – measured most often as length of stay, medical costs per client, and re-hospitalization (readmit) rates.

Far fewer studies evaluate the role of case management in providing adjustments and improvements to the client's quality of life. Most evaluations arrived at a positive assessment of case management in both these dimensions, while a smaller set of studies found null or negative correlation between case management and these outcome variables. Overall, the research to date suggests a cautious endorsement of HIV case management services as strategies in providing services to people with HIV in an effective manner.

Evaluations of HIV case management services have relied quite heavily upon systems appraisals rather than individual client outcomes. Much of the funding for evaluation has been sponsored by the Health Care Financing Administration (HCFA) which administers Medicare and Medicaid (e.g. Fleishman, Piette and Mor, 1990). Federal investments were initiated in 1986 with a \$145,000 HCFA grant to fund a study of projected Medicaid costs for AIDS. Between 1986 and 1991, the U.S. Department of Health and Human Services allocated \$43 million for 106 extramural health service research projects. Nearly 90 percent of these projects directly addressed cost, quality, and accessibility of HIV care.

Despite calls for continued evaluation of service quality and appropriateness,

Federal investments in HIV health services research has steadily declined. In 1991, Federal investments had dwindled to support for only **18** projects. In the private sector, funding to establish and evaluate centralized, **community-**based HIV case management services was initiated in 1988 by the Robert Wood Johnson Foundation as the AIDS Health Services Program (AHSP) and in 1990 by the National Community AIDS Partnership with core funding from a small group of organized philanthropy led by the Ford Foundation. Since the 1990 Ryan White CARE Act, HIV health services research from within the private foundation sector has focused on incidence and prevalence of hospitalization and related medical costs.

Different questions for different case management systems

While HIV case management services have been delivered in a variety of settings (e.g. primary, secondary, and tertiary care facilities, State and local public agencies, and community-based organizations), two types of case management, based upon the severity of the illness (early versus late), predominate in the care of people with HIV. Typically, the needs of persons in the early stages of HIV infection drive community-based case management systems, while the later stages of HIV infection and AIDS diagnosis require more medical care services and thus are driven by medical-based case management systems.

The evaluation of community-based case management systems consisted initially of impressionistic information from clients and case managers and reflected client satisfaction with services, improved access to care, and provision of basic needs such as food, shelter, and clothing (Odets, 1995; Gant and Ostrow, 1994).

Medical case management systems had different outcome criteria. Fairchild et al (1990) noted the critical importance of assessing reductions in medical costs in evaluating the provision of HIV case management within the 500 community health centers (CHCs) funded by the Federal government. Driven by escalating insurance and medical related costs, evaluations of both **community- and medically-based programs** shifted to a focus on cost effectiveness, containment, length of stay, and readmission rates.

With very little exception, this latter emphasis characterizes most contemporary HIV evaluations. Shortly after the implementation of the Ryan White CARE Act, numerous studies of evaluations and assessments of

HIV case management emerged. In contrast to the generally favorable cost-based outcomes of case management, these later evaluations, reflecting quality of life issues, presented a complicated perspective, which often reflected ambivalent and negative appraisals of case management services.

Consistently, gay white males indicated greater satisfaction with case management services than either gay males of color, women, or injection drug users (Gleason-Comstock, 1996). Further, people with greater financial and material resources evaluated case management services more positively than people with fewer resources.

The interpretation of the integration of cost and client data streams is problematic. Given the disparities of client responses, decisions regarding the composition and implementation of services have relied on cost-related data. Recently, researchers have proposed an evaluation framework that integrates cost and client-focused data in a complementary fashion (e.g. Aday et al., 1994; Marconi et al., 1993).

Positive outcomes of HIV case management

Adjustment to life situations and reduced frequency of hospitalization

Case management has been shown to be cost effective for people living with HIV, to significantly decrease total inpatient hospital cost, and significantly increase client's length of life. (Sowell et al., 1992). Early evaluation of case management systems focused upon analysis of client files, number of clients enrolled, number of clients tested, client referral patterns, length of stay, and cost per client (Piette, Fleishman et al., 1992; Gardom, Jones et al., 1989).

Liou and Cruise's (1994) study of the HIV case management model in Florida (Comprehensive AIDS Program or CAP) analyzed the impact of case management on inpatient hospitalization by examining length of stay and number of inpatient hospitalizations per calendar year. Data from 85 clients were compared with data from an ongoing study of nine projects funded by the Robert Wood Johnson Foundation. People with HIV disease in the CAP program reported significantly shorter length of hospital stays, a slightly higher rate of hospital admissions, and lower associated hospital costs when compared with national costs for similar services.

Wright et al. (1993) evaluated case management activities with a 62-item survey of nurse case managers in the California Pilot Care and Waiver Projects for HIV patients by having nurse case managers, social workers, and site directors complete the survey. Significant differences appeared in ratings among the groups on five items. Nurse case managers indicated that a wide variety of nursing skills are used to provide case management services to

persons living with HIV. According to the authors, this survey validated the interdisciplinary case management model in a community-based HIV population.

Devine et al. (1990) evaluated California's case management pilot using case management hours, client utilization of direct care services, and tracking of payment sources. Each month, projects reported to the California Department of Health Services, Office of AIDS, hours of attendant, home nurse, occupational and physical therapy, mental health counseling, practical and emotional support, social worker, homemaker, home health aid, and volunteer services utilized by each client enrolled in comprehensive case management projects during the fiscal year. This generated a project management system, from which was generated total hours of care for all clients, client months of direct service, a determination of per client use rates, and identification of payment sources.

Occasionally, case management evaluation outcomes focus on specific behavioral changes of clients. In an evaluation of case management services through community health centers (Miami, New York City, and Newark, New Jersey) between 1989-1991, 61 clients were asked the following five questions at two points in time (during the first follow-up visit and 4 to 6 months after the first follow-up visit):

1. Have you had sex with anyone in the past 30 days?
2. How many persons have you had sex with in the last 30 days?
3. How many of these were new sexual partners (persons you have not had sex with before)?
4. Did you have a regular (steady) partner during the past 30 days?
5. During the past 30 days, did you use condoms with your regular (steady) partner?

The authors concluded that while no control group was used, the findings suggested the ongoing delivery of client services was correlated with reduced sexual risk behavior. The authors discuss the limitations to the study, including small sample size, lack of control of severity of illness, and lack of information prior to the first testing period (MMWR, 1993a).

Schull (1992) investigated the clinical impact of case management using indicators of costs (length of stay: LOS) and quality of patient care (hospital re-admissions). Patients in this study were hospital admissions involved in medical case management services between 1989 and 1991 with diagnoses of HIV, AIDS-related complex (ARC), or AIDS. LOS and readmission rates

were compared to average LOS and readmit rates from **1986-1987** (prior to the availability of medical case management). Comparing the average LOS and readmit rates between the **1986-1987** and **1989-1991** periods yielded decreases of 22 percent in both the LOS and hospital readmit rates. The authors concluded that LOS and readmit rates were useful indicators of case management effectiveness, and that LOS and readmission rates are significantly reduced by the role of an inpatient-based clinical nurse specialist and case management system.

Quality of life evaluations

Numerous surveys are available concerning client and patient satisfaction with HIV case management systems. There are, however, very few published evaluations that systematically examine changes in patient quality of life.

In an evaluation of a post-release program for HIV-positive inmates, DeCiantis et al (1992) examined a collaborative project of the State Departments of Health and Corrections in Rhode Island that provided pre-release counseling, referrals to community-based support services, and case management to HIV-positive released inmates. Of the 16 HIV-infected inmates discharged, all were referred to hospital HIV clinics for medical follow-up, one to a methadone maintenance facility, and 19 to outpatient drug treatment agencies. All were successfully reunited with their families. The recidivism rate remained at zero (versus 33 percent for re-incarceration prior to program implementation). Rips et al (1992) report a similar pattern of findings for prison-based case management systems in the New York State Department of Correctional Services. Finally, an examination of the impact of community-based case management systems for chronically homeless HIV infected persons in Boston by Haggerty and O'Connell (1989) reported significant increases in client referral and client compliance with appointments and medical care regimens.

Negative outcomes of HIV case management

Lack of relationship between case management and positive client outcomes
An analysis of people with HIV disease receiving managed care service found few differences in comparison with clients not in the project, except that the project participants had more visits to clinics and longer (and higher-cost) hospital stays (Sowell et al., 1993, 1994). Another study found that hospital cost savings were offset by increased community care expenditures (Aday et al., 1994). Indeed, with the increased use of medical services, greater availability of more effective prophylaxis against opportunistic infections,

and longer life expectancies, overall cost for care will easily increase (Odets, 1995).

Cost and cost-effectiveness of HIV case management

Cost effectiveness evaluations have increased in importance as budget constraints and service reductions have affected social service funding patterns in general and HIV funding in particular. In discussing the impact of merged community-based and hospital-based case management systems in Detroit, Michigan, Finch et al (1993) collected and analyzed information on cost savings and cost-effectiveness of managed HIV care. Brodeur and Pfeferman's (1992) review of medically based case management provided by the Fairfax Hospital System HIV Center (Fairfax, VA) also describes evaluation of case management service effectiveness using cost-benefit and cost-effect analysis.

The results have been contradictory and divided. Some studies show favorable economic associations for case management (Statewide Health Council, 1990; Liou and Cruise, 1994). Other studies found that clients under HIV case management showed worse progress at higher costs (Robert Wood Johnson Foundation, 1990).

Most cost analyses use LOS as an outcome variable. LOS patterns are frequently a function of case mix. Evaluations using length of stay typically use the standard LOS (as defined by the US. Department of Health and Human Services) for the diagnosis-related group (DRG) to which the admission was assigned. For example, mild disease is a standard LOS of 3.5-8.6 days; moderate disease is a standard LOS of 8.7 days; and severe disease is a standard LOS of 8.8-22.7 days. Case mix also was assessed by the ratio of mean actual LOS to mean standard LOS for the appropriate DRGs.

A smaller number of articles discuss discharge delay resulting in unnecessary hospital days as a factor in extending length of stay. Reasons for the delays include delays in scheduling tests, delays associated with research protocols, or difficulty coordinating out-of-hospital care placement (e.g. awaiting sub-acute facility, psychiatric facility, or hospice placements, difficulty obtaining insurance information, delays in clinical decision making, resistance to plan by patient and family) (Hunter-Young et al., 1990).

Kouri, Shepard et al. (1991) examined mean LOS and annual cost of inpatient care per AIDS patient before (1987) and after (1988) the implementation of a medical case management service model in San Juan, Puerto Rico. They reported a 47 percent reduction in LOS and 74 percent reduction in inpatient

care costs. The authors further concluded that application of case management strategies from industrialized countries to developing countries was possible and, in this instance, successful. Additionally, the researchers discussed improvements and enhancements in both hospital and non-hospital services, including increased outreach services, and community and in-service HIV education and counseling services. (Ironically, the researchers noted that hospital employees received between one and threefold raises in salaries during the first year of medical case management.)

Reviewing the impact of case management services for pediatric HIV-infected patients in Montreal, Samson et al (**1992**) reported significant (50 percent) decreases in LOS between **1981-1986** and **1987-1991**. Direct and indirect costs of care were estimated by simultaneous equation-allocation methods; a more modest but still significant decrease in medically-related care costs was determined.

Community resources

Effectiveness in HIV case management is related to the ability of front-line staff to consistently and effectively identify, develop, access, and link clients to available community resources. It has been suggested while impoverished people with HIV disease generally have information about HIV service systems, they often are not able to use these services without assistance due to other co-occurring barriers or life stresses (e.g. needed child care, transportation, lack of disability benefits) (Gleason-Comstock, 1996; Gant, 1996).

Case management outcomes and client outcomes are related to the availability of relevant community resources and supportive agency structural factors and supportive community system factors. Intagliata (**1982**) urged administrators of case management services to endorse a systems perspective incorporating collaboration with other service sectors. HIV case managers can be helpful in documenting gaps in current services as can people with HIV. It is important to note that a given community's resource scarcity may mean that the needs of clients in case management systems may remain unmet despite the efforts of the best, most dedicated and resourceful case management worker.

There is increasing consensus that current configurations of case management services provide essential services. However, studies of case management services reveal inefficiencies and patterns of inequitable service delivery as well.

Evaluation strategies

In this chapter, the evaluation of case management services for people living with HIV disease has been reviewed. We come now to several critical questions regarding evaluation of these service strategies. Four major questions frame the problem:

1. How can case management services best be evaluated?
2. To what types of outcomes can these case management strategies fairly be held accountable?
3. To what extent should other external or environmental factors be taken into account in judging their effectiveness?
4. What types of evaluation techniques most appropriately capture their impacts?

As the literature reviewed in this paper indicates, traditional evaluation techniques have substantial limitations when applied to inclusive, avowedly comprehensive services. Evaluation strategies are needed to track the progress of these service efforts and to justify ongoing funding commitments from policy and program stakeholders. The current practice of incremental budgeting means that future financial allocations will require even more evidence and justification than current fiscal expenditures. Indeed, the promises for more services that are more efficiently delivered to greater numbers of people with HIV disease has been needed to secure significant commitments of new public funding.

The review of evaluation approaches yields several caveats. First, using experimental designs involving randomization or random assignment voids the case management premise of community inclusiveness. Randomization and random assignment violate the assumption that services are open and available to all who need them. Second, standardized pre- and post-indices and measures are of limited use. People with HIV have different needs and therefore require different measures or scales for assessment. The process of engagement in case management services may extend for a substantial period of time, and substantial services may be provided well before the first formal assessment or data collection period. Third, the evaluation of the impact upon relevant populations is appropriate only to the extent that case management services are available to all members of the population.

Currently, the implementation of HIV case management services has not been at a scale sufficient to produce an impact on outcomes on a community, city, or regional basis. Especially for programs serving socially and

economically disadvantaged communities, the needed level of commitment and services is extremely high. The needs routinely exceed the appropriations of funding that even the most highly regarded and respected case management initiatives have achieved. Finally, as the case management planners seek to develop a new service paradigm (whether or not the intention was to do so), the transition costs and impacts will cloud the long-term potential to achieve results.

Recognizing the limitations of current evaluation techniques in assessing the impacts of case management services, several subjects for consideration in developing outcome-based evaluation systems raised by Marconi et al. (1993) and Aday et al. (1994) are outlined here.

Service penetration

One premise of HIV case management strategies is that they will reach people with HIV who are currently untouched by current systems of medical, social, and psychological care. Indeed, the assumption is that the services will succeed after other services strategies have failed. In fact, outstanding case management programs often cite strongest success with people with HIV for whom referral connections were established only after persistent and innovative outreach. Therefore it is essential to determine the extent to which HIV case management services reach the clients for whom they are designed. This constitutes a challenge for case management services seeking to be inclusive since the most motivated and connected clients are those most likely to seek services first.

Measuring service penetration also is important in establishing the proportion of all clients who could benefit from service who are being reached. New and existing HIV case management systems cannot reasonably expect to have an impact upon the target communities unless they serve a substantial portion of the community. Furthermore, if the systems serve only a very small proportion of people with HIV, their capacity for synergy and for initiating other community changes is significantly reduced.

Client engagement

The engagement and involvement of clients also is an important early measure of service effectiveness. Outstanding programs indicate that service effectiveness is seen in the extent to which clients return for services, identify with case managers or other providers, and continue involvement. Clients also may not continue their involvement: clients may terminate from the program, connect with others, or volunteer and mentor (e.g. "buddy") others. Clients may move from social isolation to a sense of connection with

OVERVIEW OF HIV CASE MANAGEMENT EVALUATIONS

the community. Therefore, a good initial measure of service impact is likely to be actual participation and retention of people with HIV in program activities.

Community embeddedness

As clients become connected with the community, services also become connected. Effective services become a resource for other public and professional service networks; they can also connect and build natural support networks and primary services. This community embeddedness is most fairly evaluated by the degree to which such services become recognized within the community by residents and by natural and professional community institutions. Surveys of residents and community institutions along with reviews of referral patterns can help determine whether services are “within the community” or “part of the community”.

System response, climate for reform and change

Quality HIV case management systems require some changes in other social service sectors, including health care, substance abuse, mental health, financial assistance, housing, and the employment community, to name just a few. Case management services can serve as a catalyst for change within other public and community institutions, especially as advocates for the best interests of their clients. It is important to evaluate the extent to which these case management strategies have served as a force for innovation and change in other institutional systems and the extent to which they have identified areas where changes in other systems need to be. It is equally as important to determine the extent to which other systems and sectors have changed as a result, and the barriers or driving forces these systems and sectors have revealed in response to that change.

Creators of social policy want easily visualized results. The efforts in many cities and States reflect the changing interest of policy developers to move from process evaluations to outcome responsibility and accountability through the use of community-wide outcome measures. Perhaps they assume that the emphasis on outcomes and resulting political pressure will influence service delivery activity, leading to improved outcomes and better service delivery.

The move toward outcome-based evaluation is a learning process for all stakeholder groups involved in HIV case management programs. While the understanding of essential shifts in service approaches to effectively research socially vulnerable people with HIV disease is expanding to some degree, there currently is little ability to generate or replicate these approaches or to

effectively target those that currently exist for people for whom the benefits are likely to be the greatest.

Currently, many States and regions are working to develop better case management systems and more sophisticated evaluation strategies. The first products are rarely flawless; people readjust and modify the product in newer iterations. This process also will occur as relevant stakeholders work to create new HIV/AIDS case management systems and to create new evaluation and accountability systems. This work is needed to inform the growth and development of service strategies that can be effective in achieving community-desired outcomes. Perhaps then answers can be provided to the most elusive and basic issue guiding the evaluation of HIV case management programs, namely the ways in which case management affects service delivery, accessibility, continuity, quality, and cost of care (Cruise and Lou, 1993).

References

Aday L. A., Pounds M. B., *Marconi* K. (1993). A framework for evaluating Ryan White CARE Act: toward a circle of caring for persons with HIV/AIDS. *AIDS and Public Policy Journal*, **9**; pp. **138-145**.

Akili-Obika A., Costa S., William N., Robeson L., Young S. (1990). Design of a database management system for an HIV prophylaxis program. International Conference on AIDS 6, June 20-23, p. 295 (abstract no. S.D.820).

Benjamin, A.E. (1988). Long-term care and AIDS: perspectives from experience with the elderly. *The Milbank Quarterly*, **66(3)**, pp. 415-433.

Bowen G.S., Goosby E.P., Aspden W., Baity R., Eichler A., Soliz R., Weissman G., Harmon R. (1992). National funding to states/cities to improve access to HIV care by underserved populations: year one of the Ryan White CARE Act International Conference on AIDS 8, July 19-24, p. D455 (abstract no. PoD 408).

Brodeur S., Pfeferman M. (1992). The HIV center: a public/private model of outpatient care for the HIV-infected person. *International Conference on AIDS 8*, July 19-24, p. 203 (abstract no. PoD 9027).

DeCiantis M.L., DeBuono B.A., Carpenter C. (1992). Post-release program for HIV positive inmates. *International Conference on AIDS 8*, July 19-24, p.

D396 (abstract no. PoD 5055).

Devine M., Falknor I?, Reyes C., Frazier T. (1990). AIDS home Health, attendant and hospice care: utilization of direct services through California's case management pilot projects. *International Conference on AIDS 6(2)*, June 20-23, p. 461 (abstract no. 4030).

elSadr W., Oleske J.M., Agins B.D. (1994) Managing early HIV infection. Agency for Health Care Policy and Research. Clinical **Practice Guidelines Quick-Reference Guide** 7, January 1994, pp. 1-37.

Fairchild P., Coolidge J., Keehn A., Kunches L., Liebling L., Mazzullo J., Stewart J., Wroblewski S., Salomon P. (1990). The role of community health centers in HIV prevention and treatment services. *International Conference on AIDS 6*, June 20-23, p. 462 (abstract no. 4035).

Falck R.S., Siegal H.A., Carlson R.G. (1992). Case management to enhance AIDS risk reduction for injection drug users and crack cocaine users: practical and philosophical considerations. *NIDA Research Monograph 127*, pp 167-80.

Fichtner R.R., Carson D.P., Covington S.E. (1993). Project Prevent: effectiveness of a peer-based outreach program that targets urban pregnant substance abusers. *International Conference on AIDS 9*, June 6-11, p. 115 (abstract no. WS-D12-2).

Finch M.S., Meyers M.S., Horwitz M.A. (1993). The development of financing and service delivery methods for the managed care of people with HIV infection. *International Conference on AIDS 9*, June 6-11, p. 923 (abstract no. PoD 28-4234).

Fleishman J.A., Mor V., Piette J. (1991). AIDS case management: the client's perspective. *Health Services Research*, 26, (4), pp. 447-470.

Gant L.M. (1996). The rapids of health care: navigating without a compass. Presentation for Social Work Month, The University of Michigan Medical Center, Ford Auditorium, March 14, 1996.

Gant L.M., Ostrow D.G. (1995). Perceptions of social support and psychological adaptation to sexually acquired HIV among White and African American men. *Social Work*, 40(2), pp. 215-224.

Gardom J., Jones T.S., Hayden C.H., Stern H.A., Poppe P.O., Bowen G.S. (1989). Drug treatment centers as the nucleus for a prevention-based case management system for intravenous drug users. *International Conference on AIDS 5*, June 4-9, p. **138** (abstract no. W.A.P.109).

Gleason-Comstock, J. (1996). Meeting the medical, personal, social and spiritual needs of persons with HIV/AIDS. Presentation at 1996 Michigan Conference on AIDS, April 24-26, 1996, Ypsilanti, Michigan.

Hagerty C.A., O'Connell J.J. (1989) Evaluating the outcomes of a linkage system designed to facilitate access for chronically homeless persons to an outpatient AIDS program. *International Conference on AIDS 5*, June 4-9, p. 481 (abstract no. B.506).

Holzemer W., Rappoport C., Shervington W., Hein K., Shulman L., Moon M. (1993). The HIV Panel. Agency for Health Care Policy and Research (AHCPR). Guidelines for pregnancy counseling of women with early HIV-infection. *International Conference on AIDS 9*, June 6-11, p. 863 (abstract no. PoD 15-3871).

Hunter-Young N., Ricardi M., Gallagher D., Daley J., Graf L., Makadon H. (1990). Patterns of discharge delay and resulting financial impact for AIDS related admissions. *International Conference on AIDS 6*, June 20-23, p. 284 (abstract no. F.D.809).

Intagliata J. (1982). Improving the quality of community care for the chronically mentally disabled: the role of case management. *Schizophrenia Bulletin*, **8**, pp. 655-674.

Kouri Y.H., Shepard D.S., Borrás F., Sotomayor J., Gellert G.A. (1991). Public health: improving the cost-effectiveness of AIDS health care in San Juan, Puerto Rico. *The Lancet*. June 8. **337**(8754). pp 1397-1399.

Kuehnert P., Dean B., Johnson K., O'Neil B., Rodriguez R., Sanchez C., Warren L., Williamson M. (1990). Initial experience with comprehensive case management for persons with AIDS/HIV infection at Cook County Hospital, Chicago, *International Conference on AIDS 6*, June 20-23, p. 290 (abstract no. S.D.802).

Kunches L., Fairchild P., Baitty R. (1992). Current issues in providing home care services for HIV patients in the U.S. *International Conference on AIDS 8*, July 19-24, p. D520 (abstract no. PoD 5789).

Lidz V., Bux D.A., Platt J.J., Iguchi M.Y. (1992). Transitional case management: a service model for AIDS outreach projects. *NIDA Research Monograph 127*, pp. 112-44.

Liou K.T., Cruise P.L. (1994). Assessing employee attitudes in a community-based AIDS service organization. *Evaluation and the Health Professions*, 17(3), pp. 273-289.

MMWR (1993a). HIV Prevention through Case Management for HIV-Infected Persons-Selected Sites, United States, 1989-1992. *Morbidity and Mortality Weekly-Report (MMWR)*, June 18. 42(23). pp 448-449, 455-456.

MMWR (1993b). Current Trends: Assessment of Street Outreach for HIV Prevention-Selected Sites, 1991-1993. *Morbidity and Mortality Weekly Report (MMWR)*, 1993 Nov 19. 42(45). pp 873, 879-880.

Mangos J.A., Doran T., Aranda-Naranjo B., Rodriguez-Escobar Y., Scott A., Setzer J.R. (1990). Pediatric AIDS: systematic approach to patient management. *Texas Medicine* 86(4) April, pp. 40-42.

Mantell J.E., Shulman L.C., Belmont M.F., Spivak H.B. Social workers respond to the AIDS epidemic in an acute care hospital. *Health Social Work* 14(1), February 1989, pp. 41-51.

Massey E., Vincent I?. (1993) Case management and home care in rural North America. *International Conference on AIDS 9*, June 6-11, p. 519 (abstract no. PoB 34-2303).

Marconi K., Weissman G., Van Ness P., Bowen G.S., Schneider D., McClain M. (1993). Creating an agenda for research and evaluation: HIV service delivery, the Ryan White CARE Act and beyond. *International Conference on AIDS 9*, p. 947. (abstract no. PoD 36-4375).

Odets W. (1995). Why we stopped doing primary prevention for gay men in 1985. *AIDS and Public Policy Journal*, 10(3), 3-21.

Piette J., Fleishman J.A., Mor V., Thompson B. (1992) The structure and process of AIDS case management. *Health Social Work* 17(1), February, pp. 47-56.

Rips J., Sharp V. (1992) Training prison health care workers in HIV-related

primary care. International Conference on AIDS 8 July 19-24, p. D464 (abstract no. PoD 5467).

Robert Wood Johnson Foundation (1990). Proceedings: AIDS prevention and services workshop, February 15-16, 1990. Princeton, N.J.: Robert Wood Johnson Foundation.

Samson J., Lapointe N., Contandriopoulos A.P. (1992) Economic impact of pediatric HIV infected patients and model of care delivery. **International Conference on AIDS 8**, July 19-24, p. D470 (abstract no. PoD 5503).

Sherman J.J., Johnson P.K. (1991). Nursing care management. *Quality Assurance-Utilization Review*, 6(4), 1991 Winter, pp. 142-145.

Schull D.E. (1989). Clinical impact of case management by an inpatient AIDS clinical nurse specialist on costs and quality of patient care. **International Conference on AIDS 5**, June 4-9, p. 272 (abstract no. M.B.P.302).

Schull D.E. (1992). Clinical impact of case management by an AIDS clinical nurse specialist on costs and quality of patient care. **International Conference on AIDS 8 (2)**, July 19-24, p. D471 (abstract no. PoD 5504).

Seward J., Follansbee S., Christianson B. (1992). Development of a computer database system to assist patients with enrollment into an HIV clinical trial. **International Conference on AIDS 8(2)**, July 19-24, p. B237 (abstract no. PoB 3879).

Shulman L.C., Mantell J.E. (1988). The AIDS crisis: a United States health care perspective. **Social Science and Medicine**, 26, (10), 979-988.

Shulman L.C., Rappoport C., Holzemer W., Hein K., Shervington W., Moon M. (1993). Guidelines for the use of case management in early HIV infection. The HIV Panel, Agency for Health Care Policy and Research (AHCPR). **International Conference on AIDS 9**, June 6-11, p. 866 (abstract no. PoD 15-3888).

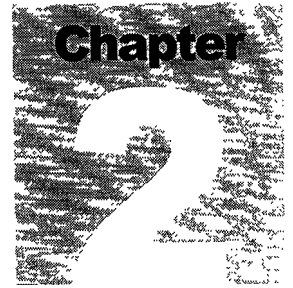
Silverman D.C. (1993). Psychosocial impact of HIV-related care giving on health providers: a review and recommendations for the role of psychiatry. **American Journal of Psychiatry**, 150(5), pp. 705-712.

Sowell R.L., Sinclair S., Hillman S. (1993). The AID Atlanta case

management system. *International Conference on AIDS 9(2)*, June 6-11, p. 950 (abstract no. PoD 36-4395).

Sowell R.L., Meadows T.M. (1994). An integrated case management model: developing standards, evaluation, and outcome criteria. *Nursing Administration Quarterly 18(2)*, Winter, pp. 53-64.

Wright J., Henry S.B., Holzemer W.L., Falknor P. (1993). Evaluation of community-based nurse case management activities for symptomatic HIV/AIDS clients. *Journal of the Association of Nurses in AIDS Care 4(2)*, April-June, pp. 37-47.



Research Design Issues in Evaluating **the Outcomes of Case Management for Persons with HIV**

John A. Fleishman, PhD¹

Case management programs have emerged as a central component of the array of services provided to people with HIV infection. The key role of case management has been institutionalized in the Ryan White CARE Act, which mandated funding for case management. Under Title II of the CARE Act, HIV care consortia established by each State provide case management to ensure service coordination and continuity (Aday et al., 1994). In the first year of funding under Title I of the Act (1991), which provides emergency assistance to specified metropolitan areas, \$9.6 million were allocated to case management by the **16** then-eligible communities; this was **13** percent of total funding (Bowen et al., 1992).

The policy emphasis on provision of case management services to people with HIV infection has developed largely on the basis of anecdotal reports and indirect evidence. Early in the history of the HIV epidemic, a network of community-based providers of HIV-related services emerged in San Francisco. In conjunction with data showing that inpatient lengths of stay were shorter in San Francisco than in New York (Arno and Hughes, 1987), the “San Francisco model” was used to argue that community-based care was preferable to more institutionally-based systems both in terms of cost savings and in terms of satisfying patient preferences to remain in the community.

¹ Dr. Fleishman is with the U.S. Agency for Health Care Policy and Research, Center for Cost and Financing.

Subsequently, demonstration programs funded by The Robert Wood Johnson Foundation and by the Health Resources and Services Administration attempted to export the San Francisco model to other communities (Jellinek, 1987). These demonstration projects became the basis for the CARE Act, and in the process served to emphasize the central role of case management.

Case management is seen as essential in a community-based care system. As has been widely noted, advances in clinical management have transformed HIV infection into a chronic disease, with ambulatory medical care playing a key role. People with HIV infection may need a wide array of services, such as transportation to medical providers, enrollment in income support and Medicaid programs, housing, substance abuse treatment, and emotional counseling. Accessing these services in a timely manner requires a sophisticated knowledge of the service delivery system and the eligibility requirements of different providers. Individual patients may lack this knowledge. In this context, the case manager assumes an important role in formulating a coherent plan of service and in shepherding the patient through the Byzantine complexities of the service system. The end result, it is argued, will be improved access to services, better quality of care, heightened quality of life, and potentially reduced aggregate costs of care for people with HIV infection.

Unfortunately, a large, systematic body of data confirming the efficacy of case management for people with HIV infection does not exist at present. The goal of this paper is to outline methodological problems that will be encountered in designing quantitative research to examine the outcomes of case management, and to review the limited quantitative evidence that has been reported to date.

What is the Question?

As all students in introductory research design courses are admonished, the first step in a research project is to achieve clarity on the hypotheses to be investigated. The argument of this paper is that the question, “Does case management work for people with HIV infection?” is too broad and simplistic. The issues must be refined and focused. Each term in the question – “case management,” “work,” and “people with HIV infection” – requires further specification.

In this regard, conducting research on the outcomes of case management is analogous to doing research on the outcomes of psychotherapy. In both

cases, the intervention is multi-faceted and complex; it is not clear what aspect of the intervention, or what combination of aspects, is responsible for any change that occurs. In addition, practitioners may adhere to different schools of thought that may shape the nature and content of the intervention. Moreover, the intervention may be successful for some people and have no effect for others; or, more realistically, some versions of the intervention may have more impact in certain cases, while other versions are more efficacious in others. Further, the outcomes to be affected also may vary, with some variables showing a beneficial impact and others remaining unchanged.

During the past several decades, a voluminous literature on the process and outcomes of psychotherapy has accumulated (**Bergin and Lambert, 1994**). In general, psychotherapy does have a beneficial effect (**Lambert and Bergin, 1994**), but reaching this conclusion took several decades and hundreds of studies. The research questions have now been refined, so that investigators ask “What type of therapy affects what kinds of outcomes for what types of patients?” By analogy, it may take years, if not decades, to develop a systematic body of data on the outcomes of case management.

Any quantitative study of the outcomes of case management must define: (1) the nature of the case management intervention; (2) the training and qualifications of the case managers; (3) the characteristics of the clients; and (4) the outcomes to be affected. Making these decisions is far from trivial or straightforward.

Case Management Program Features

Various definitions of case management have been proposed, and there is no standard case management intervention (**Weil, 1985; Applebaum and Austin, 1990**). Most descriptions of case management list core activities performed by case managers. In general, these core activities include: conducting a personalized needs assessment, developing an individualized and comprehensive care plan, arranging the provision of needed services (i.e., referral and linkage), advocating on behalf of the client, and monitoring the client, with revisions to the care plan as appropriate (**Weil, 1985; Honnard, 1985; Phillips, Kemper, and Applebaum, 1988**).

“Construct

validity” refers to the “validity with which we can make generalizations about higher-order constructs from research operations (Cook and Campbell, 1979).”

This is a multifaceted intervention. It is not clear if changes in client outcomes should be attributed to one specific component, to a subset of them, or to all components acting synergistically. One might ask, for example, “to what degree any effect of case management changes, depending on the frequency or extent of monitoring efforts?” Such a research question attempts to isolate the effect of a single component of case management. Whether such a question makes sense depends on whether one views case management as a holistic intervention or as a combination of individual components.

The multifaceted nature of case management has implications for the construct validity of a study.

Consider two groups, one of which receives case management while the other does not. One person might interpret a difference between the groups as reflecting the linking and advocacy process; a second might attribute differences to periodic monitoring; a third might conclude that the mere attention to and interest in the client displayed by the case manager was the true cause of the difference. If the concept of case management remains vague or multifaceted, a fine-grained interpretation of study results is difficult.

Further complicating the issue, specific programs may differ in terms of several dimensions:

- . Austin (1992) contrasts broker, service-management, and managed-care models of case management. Kane et al. (1991) similarly consider broker, purchase authority, **capitated** and fee-for-service models in long-term care for the elderly. When acting as brokers, case managers attempt to obtain the widest range of appropriate services for their clients; when acting as gatekeepers, case managers consider the overall cost implications of service provision and have incentives to restrain costs. The typical emphasis among HIV-related case management programs seems to be the broker and advocate role (Mor et al., 1994, but this may change as managed care programs become more widespread, especially in Medicaid programs.
- Case management programs differ in the extent to which staff are expected to advocate for system-level changes and expansion in available services (Mor et al., 1994).
- . Some programs emphasize provision of psychosocial counseling to

clients; in other programs, the psychotherapeutic aspect is minimized.

- Programs vary in the extent to which case managers actually control resources to purchase services. In some programs (e.g., for the elderly), case managers can authorize or deny services; in other programs, case managers must rely on their personal relationships with staff at other agencies to expedite service provision. Austin (1983) points to the degree to which case managers have authority for allocation of services as an important program feature.
- Case managers in some programs have the opportunity to visit clients in their home settings to assess the social environment; other case managers see clients only in the office setting.
- Some programs use a multidisciplinary team to provide case management, while others rely on individual case managers.
- Case management programs vary in the size of individual case manager's caseloads. A case manager with the luxury of a small caseload, other things being equal, may be expected to be more effective than one laboring under an excessive caseload.
- Programs vary in the nature of triage criteria. Some programs have explicit triage criteria and provide full-scale case management only to clients with severe service needs. Other programs offer case management to all who request it, including family members of persons with HIV infection.

These program variations affect the external validity of a study. In research on psychotherapy, a study using a behavioral approach may not shed light on psychodynamic therapy. Analogously, the variation in the nature of case management means that results obtained from one particular program may not be applicable to a differing program.

"External validity" refers to the extent to which the study's results can be generalized to other settings or populations (Cook and Campbell, 1979).

Psychotherapy researchers have come to realize the importance of carefully describing the intervention (Kazdin, 1994). Some studies actually develop a therapy manual, which provides criteria for clinical decision-making in particular circumstances. In assessing the effects of case management, it is similarly important to provide as detailed a description of the program as possible. Such a description not only enables consumers of the research to appreciate the generalizeability of the findings, but also facilitates replicating

the program in other settings, should it prove to be successful.

Client Characteristics

During the past decade, HIV infection has spread from the gay community to other sociodemographic groups, such as people of color, injection drug users, and women. The diversity of people living with HIV is increasing. This diversity has implications both for the delivery of case management and for the evaluation of case management. Greater client diversity heightens the need for cultural sensitivity in appreciating a client's problems, and forces programs to link with a wider array of providers, such as substance abuse treatment or foster care programs.

Client variability is a key issue in evaluating case management. Clients may respond to the same program in different ways. It is unlikely that, even if case management could be standardized for all clients, its effect would be uniform. At a minimum, client variation in the impact of case management will increase error variance in statistical models and result in lower power for rejecting the null hypothesis that case management has no effect.

In addition, one would like to specify the types of clients who may benefit from a certain type of case management, and those for whom a particular program may be unsuitable. Some clients might do better in Program X, while others might benefit more from Program Y. This can be represented statistically as an interaction effect. For example, in psychotherapy research, a therapy designed for schizophrenics may not be appropriate for people with depression. Research on case management must be sensitive to the possibility that client characteristics may interact with the intervention to affect the outcome. Case management is not a "one size fits all" intervention.

For purposes of research, one approach to dealing with client variability is to make the client pool as homogeneous as possible. However, the price to be paid for this strategy is reduced external validity; the findings might not generalize to other populations. Another approach is to form blocks of relatively similar clients. Client characteristics (e.g., male and female; white, Black, and Hispanic) can be one factor in the research design. This will enable the researcher directly to test for potential interactions.

In adopting either strategy, one must consider which specific client characteristics will interact most strongly with the case management intervention. How should clients be categorized? Forming groups on the basis of sociodemographic characteristics, such as gender, race, or HIV exposure group, is most straightforward. But these variables may be acting as

proxies for other, more theoretically relevant characteristics. For example, perhaps the client's degree of trust or familiarity with the "establishment" system of care is a key factor in explaining responses to case management. Or perhaps case management has a stronger effect for clients without an informal support system, compared to those with such support.

Alternatively, it may be important to distinguish clients in terms of the specific services they need. Case management may have a stronger impact for clients who need to obtain entitlements than for those who need housing or substance abuse treatment. One difficulty with this approach, however, is deciding how to categorize clients who have different sets of multiple needs; the number of people with a particular pattern of service needs may be small; this will limit the ability to form blocks of similar clients.

Case Manager Characteristics

In studies of psychotherapy, it is acknowledged that the training and skills of the therapist will greatly affect the success of the intervention (Beutler et al., **1994**). All therapists are not alike; some are more skilled and competent than others. Similarly, case managers vary in their skills; two case managers, in the same program dealing with very similar clients, may differ in their success rates. This may depend on their ability to form a trusting relationship with clients, their knowledge of the local service system, their personal connections with staff in other agencies, etc. Consequently, evaluations of case management must specify the background and training of the case managers. It may be inappropriate to compare results of one program, in which the case managers are relatively inexperienced, with another program, in which the staff have advanced degrees and many years of experience. In The Robert Wood Johnson Foundation's AIDS Health Services Program, case managers in hospitals typically had degrees in nursing or social work.

Community-based agencies, in contrast, varied in the degree to which they required professional certification; many community organizations hired bachelor's-level staff who had some prior familiarity with HIV services or with the client population (Mor et al., **1994**). At a minimum, evaluation reports should describe staff in terms of the number of years they have been providing case management services.

The proper background and training of case managers is a persistent focus of debate. Some argue that nursing is the preferred background for case managers in HIV services, while others favor training in social work. A survey of HIV case managers in several cities across the country found that

both nurses and social workers were engaged in case management (Piette et al., 1990), with nurses predominating in clinic settings and social workers more frequent in community-based organizations. Nurses and social workers may differ systematically in the manner in which they implement case management, and ignoring such variation may bias the interpretation of evaluation findings.

Outcome Variables

As suggested above, a number of variables may potentially respond to case management. Possible outcome variables include:

- . Utilization of ambulatory medical services;
- . Unmet needs for medical or social services;
- . Quality or appropriateness of medical care (e.g., are case-managed individuals more likely to receive prophylaxis for *pneumocystis carinii* pneumonia (PCP), compared to those without case management?);
- . Measures of psychosocial adjustment or quality of life;
- Duration of survival from time of AIDS diagnosis;
- . Costs of providing medical and social services; and
- Degree of service coordination.

These variables may respond differently to a case management intervention. For example, efforts to ensure that clients obtain all the services they need may increase utilization, reduce unmet needs, but also increase the overall cost per case. Evaluations of case management must therefore carefully consider which outcome variables are most central and important to measure.

Some outcomes, such as extent of unmet service needs or psychosocial adjustment, may be directly or proximally affected by case management. In contrast, other outcomes, such as length of survival, may be more distal, indirect, and influenced by a number of factors in addition to the intervention. While a comprehensive evaluation would examine both proximal and distal factors, it may be expected that any impact of case management will diminish as the outcome becomes more distant from the intervention. Thus, a number of clinical factors may influence survival in addition to receiving case management, and any comparison of the survival of people receiving and not receiving case management would have to consider such potentially intervening-factors.

Other Research Design Issues

Several other niceties of research design must also be considered when planning or assessing an evaluation of case management.

Sample Size

The number of clients participating in the study is a fundamental consideration. If the study inducts too few clients, insufficient information will be generated to detect true differences between treatments (i.e., statistical power will be low). A small sample also inhibits the development and testing of multivariate statistical models. It is now commonplace to estimate statistical power for a range of sample sizes prior to initiating a study. Several studies of case management for the chronically mentally ill have reported non-significant effects for case management. Unfortunately, most research that reports no-difference findings does not present calculations of the statistical power of the tests. Some negative results may have resulted from lack of statistical power.

Number of Case Managers

In addition to the number of clients, the number of case managers participating in the study is important. At the extreme, if only one case manager delivered the intervention, then any differences between treated and untreated clients might be due to the unique capabilities of this person, and not due to the treatment. Ryan et al. (1994, who studied 20 case managers serving mentally ill clients, found large differences in outcomes as a function of particular case managers. Having multiple case managers deliver the intervention facilitates interpretation of differences in outcomes, because differences are unlikely to be due to a single individual. Having multiple case managers also enables examination of potential effects of variations in the training or background of case managers. Unfortunately, some studies neglect to report a basic datum: the number of participating case managers.

Clustering within Case Managers

Standard statistical models assume that each client's outcomes are unrelated to the outcomes of other clients (i.e., that the observations are independent). This assumption is violated in evaluations of case management. Specifically, clients of the same case manager are collectively influenced by that case manager's individual characteristics and style. Because they share these influences in common, clients cannot be considered independent observations. (Analogously, students in a classroom taught by the same teacher cannot be considered independent in evaluations of educational interventions.) The effect of ignoring this clustering is to bias estimates of

standard errors, which then biases the outcomes of statistical tests of hypotheses. The preferred approach is to treat clients as nested under their common case manager, and statistical techniques for correctly estimating such hierarchical models have been developed (Bryk and Raudenbusch, 1990).

Organizational Setting

Case management for people with HIV infection takes place in a number of different settings, most often in community-based organizations and in hospitals (Piette et al., 1990; Mor et al., 1994). The organizational locus of case management may systematically affect client outcomes. For example, compared to community-based case managers, hospital-based case managers may have easier access to clinical trials for their clients, or their access to medical records may facilitate documenting the client's condition for the purpose of determining eligibility for some programs (e.g., documenting an AIDS diagnosis to obtain Medicaid). In contrast, community-based case managers may work for organizations that directly provide support groups, buddies, or meal delivery, and they may thus be more able than hospital-based staff to enroll clients in such programs. Organizational setting will shape the particulars of a case management program; providing information on the organizational setting will enhance construct validity. In addition, including case managers who practice in different organizational settings will enhance the external validity of an evaluation by broadening the base from which inferences are derived.

Local System Variations

In psychotherapy, the interaction between patient and therapist should be the most important factor affecting outcome; the therapeutic process is, to some degree, isolated from external influences. In contrast, the efficacy of case management depends on the availability or cooperation of third parties – providers of other services to which the case manager is attempting to link the client. If a client needs treatment for substance abuse and there are no available treatment slots, then attempts at linkage will be unsuccessful, despite a case manager's best efforts. Consequently, the outcome of case management may depend on the characteristics of the local service delivery system. Case management in a resource-rich environment may demonstrate successful client outcomes; case management in a resource-poor or antagonistic environment may show meager effects. The effects of case management cannot be understood apart from the characteristics of the local service system.

At a minimum, evaluators should be aware of the structure and operation of

the local service system. If the evaluation is limited to one community, which reduces external validity, then a rich understanding of that community will provide a context for interpreting more quantitative outcome data. If the evaluation encompasses multiple diverse communities, which is a stronger design from the standpoint of external validity, then knowledge of each local service system can afford insight into the inevitable **inter-community** differences in mean client outcomes.

Timing of Outcome Variable Measurement

Ideally, outcome variables should be measured at the point in time at which the change process has been completed. Unfortunately, there are few theories of change that specify how long it will take to change aspects of client functioning. In psychotherapy research, one might not expect to see significant client improvement after one or two sessions; if the evaluator administers outcome measures too soon, subsequent change will not be recorded and the intervention might falsely appear ineffective. If a change in substance abuse behaviors is one outcome of case management, the evaluator might have to wait several months (or longer) before assessing change. In one study of case management for severely mentally ill clients (Goering et al., 1988), experimental subjects performed significantly better than control subjects in occupational functioning and independent living, but this difference appeared at the **24-month** post-test and was not evident at 6- and 9-month post-tests.

The situation is made even more complex if multiple outcome variables are examined. Each might have its unique rate of change. Suppose that the outcome of interest is the number of unmet service needs. A **meals-on-wheels** service might be instituted rapidly, while housing assistance or receipt of Supplemental Security Income might take longer to obtain. While administering outcome measures too soon may miss subsequent improvement, waiting too long may result in new service needs arising, or previously resolved service needs becoming problematic again. Life circumstances of clients are in a constant state of flux, especially so in the case of HIV infection, with its bursts of acute clinical episodes. At what point to take a snapshot of this changing stream requires careful thought.

Experimental and **Quasi-experimental** Designs

The literature on program evaluation is replete with discussions of the advantages and disadvantages of different research designs. The true experiment is considered to be the optimal design for the purpose of maximizing a study's internal validity.

“Internal validity” refers to the approximate validity with which we infer that the relationship between two variables is causal (Cook and Campbell, 1979).

The hallmark of the true experiment is the use of a random process to assign subjects to receive a particular treatment (or to receive no treatment). Random assignment ensures that the groups of subjects in the several treatment conditions are statistically equivalent. This equivalence facilitates comparisons of the different treatments and enables an unbiased estimate of the effect of each treatment to be calculated. In contrast, a quasi-experiment establishes comparisons between different groups (or the same group at different times), but random assignment to a particular treatment condition is absent.

Ethical Considerations

Implementing a true experiment in real-world settings is fraught with difficulties (Berk, 1990). Some of these are ethical in nature. A simple research design would compare a group receiving case management to another group that did not receive case management. If a no-treatment control group is part of the design, the evaluator must consider the propriety of withholding case management from some people who might benefit from it. An argument could be made that, since the benefit of case management is not known (if we did, we'd have no need for the research), we are not necessarily withholding something valuable from people in the control condition. Further, if the study finds that case management has minimal impact, then scarce resources can be devoted to more beneficial uses. If the study finds that case management is beneficial, this provides compelling justification for continued, if not increased, funding. It is much easier to find methodological reasons for dismissing the results of a quasi-experiment than for a true experiment (Berk, 1990).

Despite these arguments, many researchers are reluctant to implement no-treatment conditions. One expedient used in psychotherapy research is to use a waiting-list control group; people in this group are told that they will receive therapy, but they have to wait some time before a therapist is available. Clients receiving therapy are then compared to those in the waiting-list group, before therapy begins for the latter. In the case management context, an initial needs assessment could be conducted, in conjunction with information and referral to service providers. Such an approach may still be untenable for people with HIV, since the receipt of services may literally be a matter of life and death. It would be difficult to tell a client in crisis to wait for services until the dictates of the research design were satisfied.

Another design expedient is to compare alternative versions of the intervention. Case managers with masters degrees in social work could be

compared to those with baccalaureate nursing degrees, or frequency of monitoring activities could be systematically varied, or case managers with authority to purchase services could be compared to those without such authority. This type of design can provide useful information for examining the effects of the components of case management. This design cannot, however, answer the question of the effect of case management compared to no intervention.

Treatment Integrity

Assessing the impact of case management requires that the intervention actually be delivered in the appropriate manner. Randomized assignment will be wasted if the intervention is not really provided, or is provided sub-optimally. This is not a hypothetical possibility. In the evaluation of the AIDS Health Services Program (AHSP), we discovered that some providers had experienced a large influx of clients with no corresponding staff expansion. This resulted in very high caseloads for each case manager. In one site, there were five case managers and over 1,000 clients; in others the client-to-case-manager ratio was well over 100 (Mor et al., 1994). A skeptic would wonder whether any case management was really occurring when caseloads were so high.

Interviews with clients raised similar issues. Although all respondents were enrolled in the AHSP and were presumably receiving case management, we found that 20 percent of clients recruited from community organizations said they had no case manager, and 46 percent of clients recruited at hospital clinics could not name a case manager. Among those clients who had a community-based case manager, 18 percent reported no contact in the previous month, and 26 percent of those with a clinic-based case manager reported no contact in the prior month (Fleishman et al., 1991). Case managers were undoubtedly devoting more of their time and effort to those clients with greater service needs, but this resulted in an attenuated intervention for others. Including clients who received a minimal intervention in statistical analyses could result in reducing any estimated effect of case management.

At the other extreme, some clients may be receiving an enhanced intervention. This may occur when clients receive case management from multiple agencies. Nearly 10 percent of clients interviewed for the AHSP evaluation had two case managers (Fleishman et al., 1991). Anecdotal reports suggest that many people with HIV infection have multiple case managers. If some clients assigned to receive case management receive an “extra dose” of case management, internal validity of the research is compromised. More

serious, clients assigned to a no-treatment control condition may obtain case management services elsewhere. One study of case management for mentally ill clients found no differences between treatment and control groups (Franklin et al., 1987); the fact that control group clients were eligible to receive aggressive aftercare services that were very similar to those provided to the experimental group may have contributed to the no-difference finding (Rubin, 1992).

Unlike clinical trials of medications, the provision of case management cannot be rendered uniform for all clients. Whether the research is experimental or quasi-experimental, it is imperative that data be collected to document the nature of the intervention that clients actually received. In addition, people who are assumed to be receiving no intervention cannot be assumed to spend the period of the study in a state of cryogenically-frozen suspended animation; they may well be receiving equivalent services from other sources.

Participant drop-outs

Related to the issue of treatment integrity is the problem of what to do with drop-outs. A review of six studies of case management for people with mental illness found that attrition ranged from 11 to 36 percent (Chamberlain and Rapp, 1991). It is unlikely that attrition occurs completely at random. Instead, clients whose problems have been resolved, and who therefore would reflect the greatest benefit, might discontinue case management. Those people whose problems had not resolved would remain in the treatment group, and actually making case management appear to be ineffective if outcome measures are obtained on only those remaining. Alternatively, clients may be more prone to drop out if no progress is made in improving their situation; this process would make case management appear to be more effective than it really was.

Non-random attrition from experimental and control groups has been labeled “differential mortality” (Cook and Campbell, 1979). Case management for people with HIV will encounter actual client mortality. If, for example, quality of life is an outcome variable, the researcher must consider how to score this outcome for decedents. Excluding decedents from the analysis may bias the results. Studies often find a “healthy survivor” effect; if mortality was higher among controls than the experimental group, limiting the analysis to those alive at the end of the study may obscure a true difference. In short, nonrandom attrition will compromise a true experiment, and it will render the analysis of a quasi-experiment even more complex. Statistical models for incorporating attrition into the analysis of

longitudinal data are being developed (e.g., Little, 1995), but these models are complex, are not available in standard statistical software packages, and often rely on unverifiable assumptions.

Quasi-experiments

In view of the difficulties inherent in implementing a randomized experiment, some may argue for use of quasi-experiments instead. In opposition, Berk (1990) argues that true experiments have been successfully implemented, and that even flawed field experiments are “typically better than the design alternatives in which random assignment is not employed.”

The nonequivalent control group design is a common quasi-experimental approach. This design compares two (or more) groups that differ in the intervention they have received. For example, a group of people receiving case management is compared with another group that did not receive case management. Because people were not assigned to groups at random, the groups may differ in several respects. This introduces the possibility of selection biases: any obtained group differences in outcomes may be attributable to these pre-existing differences, and not to the intervention itself. For example, due to the operation of triage criteria, case management clients may have a greater array of hard-to-satisfy service needs than people not receiving case management; comparison of these two groups after receiving the intervention may show that, although both groups improved on average, the case-managed group was still worse off than the control group and had shown less improvement. This comparison may make case management appear to be ineffective. Evaluations of compensatory education programs have had to deal with this type of situation.

In an effort to reduce selection biases, investigators try to match individuals in the different groups in terms of variables that might affect the outcome. Alternatively, researchers attempt to control for group differences statistically. A large literature on statistical methods for controlling for selection biases has arisen in economics, but the proposed techniques are still controversial.

Other quasi-experimental designs involve a comparison of the same person over time, both before and after receiving case management. This approach also suffers from threats to internal validity. One threat is history: other developments that affected outcome measures may also have occurred between pre-test and post-test. For example, an influx of funds into one community could have facilitated opening a dental clinic; reduction in unmet needs for dental care among case management clients could have been caused

by this system change, and not case management.

A second threat is regression effects. This reflects the fact that health and social status fluctuates, in part at random. Someone may request case management at a time when things are going particularly badly. At a later point, the problems may have resolved themselves, even in the absence of case management (i.e., the person regresses back to a more typical status).

Cook and Campbell (1979) provide the standard treatment of quasi-experimental designs and strategies for reducing threats to validity. For present purposes, it suffices to say that interpretation of findings from a quasi-experiment is more uncertain and complex, compared to true experiments. Nevertheless, it is preferable to have a number of quasi-experimental studies than to have no data whatsoever.

Evaluation Studies of HIV Case Management

Despite the historical salience of case management programs for people with HIV infection, the body of quantitative empirical evaluations of HIV-related case management is meager. There are descriptions of particular case management programs (e.g., **Sonsel** et al., 1988; **Sowell** and Grier, 1995) and reports of individual cases (**Roberts** et al., 1992), but few published evaluation studies that address outcomes of case management at the client level.

AHSP Evaluation Results

Fleishman et al. (1991) analyzed interviews with 1,031 clients in the AIDS Health Services Program, all of whom were supposed to be receiving case management as part of their participation in the program. Their analyses contrasted clients who were recruited from community-based organizations (CBOs) with those recruited from hospital-based outpatient HIV clinics. Compared to CBO clients, clinic clients were more likely to be nonwhite and female, to have public health insurance, and to have a history of injected drug use. These contrasts illustrate potential selection biases in any simple comparison of clinic- and CBO-based case management.

As noted above, many clients could not identify their case manager by name. More than 27 percent of clients did not have an identified case manager at either a clinic or a CBO. Another 10 percent reported having both a clinic and a CBO case manager. While 25 percent of clients with a case manager reported contacting their case manager three or more times in the previous month, more than 18 percent of those with a clinic case manager and 26 percent of those with a CBO case manager reported no contact. Thus,

treatment integrity was problematic for a subset of clients.

Clients who reported needs for help applying for entitlements, for home services, for psychological counseling, and for housing assistance were more likely to report having a case manager than those without a need for each of these services. This is not surprising, in view of the fact that some programs had established triage criteria that resulted in greater attention to clients with more pressing service needs. However, if more needy people receive case management and those with fewer needs do not, then the treated and the untreated group are not equivalent, and a direct statistical comparison is inappropriate.

One approach to examining the outcomes of case management is to check whether clients received needed services. It is reasonable to hypothesize that clients who are case managed will be more likely to receive needed services than clients without a case manager. Fleishman et al. (1991) compared clients who reported having a case manager with those who reported no case manager. Having a case manager was significantly associated with receiving assistance with applying for entitlements and with receiving psychological counseling (among clients who had reported a need for each service). Having a case manager was not significantly associated with ameliorated needs for other services – such as housing, transportation, and substance abuse treatment. However, for each service a higher proportion of those who needed the service and had a case manager actually received the service, compared to those who needed the service and did not have a case manager.

Mor et al. (1994) report additional analyses of resolution of service needs, using an augmented sample of 1,386 AHSP clients. After statistically controlling for ethnicity, gender, illness severity, and geographical site, having a case manager was significantly related to a lower probability of having an unmet need for entitlements and for legal/financial advice. Case manager status (having versus not having one) was not significantly related to needs for services such as psychological counseling, transportation, housing, and substance abuse treatment. Of note, controlling for geographical site reduced associations between case manager status and unmet need for some services, including housing, dental care, and rental assistance. This finding highlights the fact that certain services may be more available in some locales than in others, and this will influence the outcomes of case management.

In summarizing their analyses, Mor et al. (1994) note that

“it is clear that certain service needs were relatively unaffected by case manager status. In general, having a case manager was only weakly related to unmet needs for dental care, drug abuse treatment, transportation, and psychological counseling. What these services had in common were their limited supply and the fact that case managers did not control availability. These data are consistent with the conventional wisdom that the usefulness of case management is limited when it involves coordinating services that are in short supply” (p. 188).

In contrast, having a case manager was consistently related to resolving needs for help applying for entitlements. This was a common activity among case managers, and the application process is under the control of case managers.

Other Evaluation Studies

McCoy et al. (1992) report a randomized trial of case management for HIV-infected injection drug users in Miami. One hundred people were assigned to the case management group, and 40 to the control group. Randomization procedures had to be altered in order to maintain a sufficient caseload for the three case managers participating in the study, illustrating the practical constraints that may affect implementation of random assignment in a field setting. Members of the control group did meet briefly with a social worker, who made appropriate referrals.

The researchers examined a number of outcome measures. The greatest change among case-managed clients was an increase in medical care utilization; in part, the case management program made clients aware of the availability of AZT and other medications. Utilization of medical care also increased among control group members, but not as greatly. It is unclear to what extent increases in utilization were due to adverse changes in clinical status, rather than to the intervention. In addition, risky sexual and drug use behaviors were assessed. In general, both case management and control groups showed reductions in risky behaviors, although a significant difference was obtained for only one of several behaviors (number of different people with whom the client both injected drugs and had sex). The authors do not report data on reduction in service needs, in part because follow-up data were not completely available.

Twyman and Libbus (1994) compared 100 deceased clients of the Missouri Department of Health’s HIV case management program to a convenience sample of 99 deceased people with AIDS who had not been enrolled in this

program, The major outcome measure, obtained from Medicaid records, was the number of inpatient days in the 6 months prior to death. No significant difference was found. As the authors note, focusing only on the 6 months preceding death may miss important differences in utilization earlier in the disease course. In addition, clients in the control group may have received case management from a source other than the Department of Health. Finally, the authors did not introduce multivariate statistical controls in their analyses, nor did they have access to detailed clinical data, which might have afforded more precise controls for disease severity.

Sowell et al. (1992) retrospectively reviewed hospital records of 150 men who had died of AIDS in Georgia. Seventy five had been enrolled in a community-based case management system and had received medical care at a large urban hospital, while the remainder were not case managed and had received medical care at other hospitals throughout the State. Patients receiving case management had significantly lower hospital charges (diagnosis to death) than those not receiving case management. Case-managed patients had slightly, but not significantly, more total days in the hospital than those without case management (39.8 versus 31.1). The design of this study had several positive features, such as including terminal care charges in the analysis and adjusting for hospital differences in charge structures. However, as the authors note, the fact that all case-managed clients received care at one hospital with extensive experience in treating HIV patients provides an alternative interpretation of the results. Differences in charges could be attributable to more efficient treatment in this particular hospital, compared to non-case-managed clients treated in hospitals with less experience. The fact that utilization was actually slightly higher among those receiving case management is consistent with this interpretation.

Conclusions

Further research is needed on the process and outcomes of case management. The present paper has described a wide array of methodological problems that beset evaluations of case management. These methodological challenges should not deter future investigations. While it may be extremely difficult to conduct a definitive evaluation study, the accumulation of results from a number of studies, each having a slightly different mix of limitations or potential biases, may form a basis for making empirical generalizations and informed policy decisions.

At this stage in the development of case management programs, it may be premature to implement a large-scale randomized field experiment. Such

large-scale studies are valuable when the intervention is well defined and standardized; this is not the case for HIV case management. Instead, there is an opportunity for a combination of qualitative and quantitative research. A qualitative component can collect rich data on the nature of the intervention as actually delivered, the barriers and constraints that staff face, and unanticipated client reactions to the intervention. Such data can usefully supplement statistical analyses of outcome measures.

We need more data on the process of delivering case management services. How large can caseloads be before the intervention becomes degraded? How can flexible guidelines for frequency of client monitoring be developed? What factors contribute to the reluctance of clients to enter case management programs? What is the prevalence of multiple case managers for individual clients? To what degree do outcomes depend on the nature of the relationship between case manager and client (e.g., trust, respect, empathy), and how can such variables be measured reliably? One theme of this paper is that differences in outcomes must be interpreted in the context of information on the process of delivering the intervention.

Designing outcome studies will be facilitated to the extent that consensus exists on what are the most appropriate outcomes of case management. Investigators should devote more thought to specifying theoretically relevant outcome measures. Although some evidence suggests that case management may not result in cost savings for other populations (Benjamin, 1988), no studies actually examine cost savings or increases attributable to case management for persons with HIV infection. In addition, guidance concerning the optimal point in time to measure particular outcomes will also contribute to stronger research designs.

As managed care becomes more pervasive in the delivery of health services, the need to compare different types of case management programs becomes more urgent. As noted, important program variations involve broker or advocate versus gatekeeper models, and whether or not the case manager controls or authorizes services. Comparisons of such program variations may provide relevant and useful information for policy makers.

Summary

Empirical evaluations of the outcomes of case management for persons with HIV infection are rare. Research has not moved very far beyond anecdotal reports. The few studies that have been reported present a mixed picture. Case management may reduce needs for certain services that are not in short

supply and may actually increase utilization of medical care and social services. Data demonstrating that HIV-related case management results in cost savings have not been reported. Studies reported to date also suffer from methodological limitations that render their findings less than conclusive. Despite the difficulty of designing evaluations of a complex, non-standardized, and changing intervention in a field setting, further research on the outcomes of case management for people with HIV infection should be undertaken and will enable policy makers to make decisions outside of a vacuum.

References

Aday, L.A., Pounds, M.B., Marconi, K., and Bowen, G.S. A framework for evaluating the Ryan White CARE Act: Toward a circle of caring for persons with HIV/AIDS. *AIDS and Public Policy Journal* 9: 138-145, 1994.

Applebaum, R.A., and Austin, C.D. *Long-Term Care Case Management: Design and-Evaluation*. New York: Springer Publishing Co., Inc., 1990.

Arno, P.S, and Hughes, R.G. Local policy responses to the AIDS epidemic: New York and San Francisco. *New York State Journal of Medicine* 87: 264-271, 1987.

Austin, C.D. Case management in long-term care: Options and opportunities. *Health and Social Work* 8: 16-30, 1983.

Austin, C.D. Have we oversold case management as a “quick fix” for our long-term care system? *Journal of Case Management* 1: 61-65, 1992.

Benjamin, A.E. Long-term care and AIDS: Perspectives from experience with the elderly. *The Milbank Quarterly* 66: 415-443, 1988.

Bergin, A.E, and Garfield, S.L. *Handbook of Psychotherapy and Behavior Change, 4th_Edition*. New York: John Wiley, 1994.

Berk, R.A. What your mother never told you about randomized field experiments. Pp. 145-155 in *Community-Based Care of Persons with AIDS: Developing a Research Agenda*. AHCPR Conference Proceedings. DHHS Publication No. (PHS) 90-3456.

Beutler, L.E., Machado, P.P.P., and Neufeldt, S.A. Therapist variables. pp. 229-269 in A.E. Bergin and S.L. Garfield (Eds.), *Handbook of Psychotherapy*

and Behavior Change, 4th Edition. New York: John Wiley, 1994.

Bowen, G.S., Marconi, K., Kohn, S., Bailey, D.M., Goosby, E.P., Shorter, S. and Niemcryk, S. First year of AIDS services delivery under Title I of the Ryan White CARE Act. **Public Health Reports 107: 491-499, 1992.**

Bryk, T., and Raudenbusch, S. **Hierarchical Linear Models.** Beverly Hills: Sage, 1990.

Chamberlain, R., and Rapp, C.A. A decade of case management: A methodological review of outcome research. **Community Mental Health Journal 27: 171-187, 1991.**

Cook, T.D., and Campbell, D.T. **Quasi-Experimentation.** Chicago: Rand McNally, **1979.**

Fleishman, J.A., Mor, V., and Piette, J.D. AIDS case management: The client's perspective. **Health Services Research 26: 447-470, 1991.**

Franklin, J.L., Solovitz, B., Mason, M., Clemons, J.R., and Miller, G.E. An evaluation of case management. **American Journal of Public Health 77: 674-678, 1987.**

Goering, P.N., Wasylenki, D.A., Farkas, M., Lancee, W.J., and Ballantyne, R. What difference does case management make? **Hospital and Community Psychiatry 39: 272-276, 1988.**

Honnard, R. The chronically mentally ill in the community. In M. Weil and J.M. Karls (Eds.), Case **Management** in **Human Service Practice.** San Francisco: Jossey-Bass, 1985.

Jellinek, P.S. Case-managing AIDS. Issues **in Science and Technology 4: 59-63, 1988.**

Kane, R.A., Penrod, J.D., Davidson, G., and Moscovice, I. What cost case management in long-term care? **Social Service Review :281-303, 1991.**

Kazdin, A.E. Methodology, design, and evaluation in psychotherapy research. pp. 19-71 in A.E. Bergin and S.L. Garfield (Eds.), **Handbook of Psychotherapy and-Behavior Change, 4th Edition.** New York: John Wiley, 1994.

Lambert, M.J., and Bergin, A.E. The effectiveness of psychotherapy. Pp. 143-189 in A.E. Bergin and S.L. Garfield (Eds.), *Handbook of Psychotherapy and Behavior Change, 4th Edition*. New York: John Wiley, 1994.

Little, R.J.A. Modeling the drop-out mechanism in repeated measures studies. *Journal of the American Statistical Association* 90: 1112-1121, 1995.

McCoy, H.V., Dodds, S., Rivers, J.E., and McCoy, C.B. Case Management services for HIV-seropositive IDUs. *NIDA Research Monograph*, 181-207, 1992.

Mor, V., Fleishman, J.A., Allen, S.M., and Piette, J.D. *Networking AIDS Services*. Ann Arbor: Health Administration Press, 1994.

Piette, J.D., Fleishman, J.A., Mor, V., and Dill, A.E.P. A comparison of hospital and community case management programs for persons with AIDS. *Medical Care* 28: 746-755, 1990.

Phillips, B.R., Kemper, P., and Applebaum, R.A. Case management under Channelling. *Health Services Research* 23: 67-81, 1988.

Roberts, C.S., Severinsen, C., Kuehn, C., Straker, D., and Fritz, C.J. Obstacles to effective case management with AIDS patients: The clinician's perspective. *Social Work in Health Care* 17: 27-40, 1992.

Rubin, A. Is case management effective for people with serious mental illness? A research review. *Health and Social Work* 17: 138-150, 1992.

Ryan, C.S., Sherman, P.S., and Judd, C.M. Accounting for case manager effects in the evaluation of mental health services. *Journal of Consulting and Clinical Psychology* 62: 965-974, 1994.

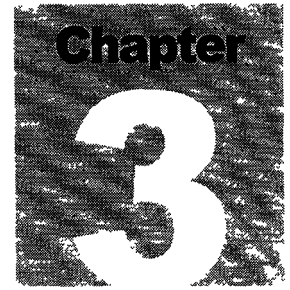
Sonsel, G.E., Paradise, F., and Stroup, S. Case-management practice in an AIDS service organization. *Social Casework* : 388-392, 1988.

Sowell, R.L., Gueldner, S.H., Killeen, M.R., Lowenstein, A, Fuszard, B, and Swansburg, R. Impact of case management on hospital charges of PWAs in Georgia. *JANAC* 3: 24-31, 1992.

Sowell, R.L., and Grier, J. Integrated case management: The AID Atlanta model. *Journal of Case Management* 4: 15-21, 1995.

Twyman, D.M., and Libbus, M.K. Case-management of AIDS clients as a predictor of total inpatient hospital days. *Public Health Nursing* **11: 406-411, 1994.**

Weil, M. Key components in providing efficient and effective services. In M. Weil and J.M. Karls (Eds.), *Case Management in Human Service Practice*. San Francisco: Jossey-Bass, **1985.**



Evaluating the impact of **HIV Case Management: Research Issues and Limitations**

*Susan Elizabeth Lehman PhD MPH, Daniel Gentry
PhD MSHA, and Edward C. Waltz PhD MS**

Case management for persons with HIV disease has been funded at increasing levels in recent years, with almost 18 percent of Ryan White Comprehensive AIDS Resource Emergency Act (CARE Act) Title I dollars targeted at case management in 1993 and 1994 (Shulman, 1996). As a result, HIV case management programs have proliferated across the country. For example, in the Baltimore Title I Eligible Metropolitan Area (EMA), Marconi and colleagues found that 19 out of 62 community agencies provided case management services, making it the most commonly offered HIV service after ambulatory medical care (Marconi et al., 1994).

Policies encouraging HIV case management¹ have been largely based on the dual assumptions that (1) case management improves client access to needed

*Dr. Lehrman is with the Graduate Management Institute, Union College, Schenectady, NY; Dr. Gentry is with the School of Public Health, Saint Louis University, St. Louis, MO; Dr. Waltz is with the State University of New York at Albany.

¹ For simplicity, unless otherwise specified, the term "case management" as used in the context of this paper refers specifically to HIV case management.

services while (2) saving health care dollars by facilitating the use of community-based versus institutional care (**Mor et al., 1989**). Unfortunately, there is a lack of well-designed research to support this latter contention in people with HIV disease (**Mor, Piette, and Fleishman, 1989; Sowell, Gueldner, Killeen, et al., 1992; Twyman and Libbus, 1994; Sowell, 1995**)². Research on case management-related cost savings in the fields of geriatrics, mental health, and maternal and child health has produced, at best, mixed results (**Kemper, 1988; Ruchlin, Morris, Gutkin, et al., 1987; Hughes, 1985; Franklin, 1987**).

The bulk of HIV case management evaluation, rather than examining savings or other outcomes, has focused on structure, process, or both (**Mor, Piette, Fleishman, 1989; Piette, Fleishman, Mor, and Dill, 1990; Piette, Fleishman, Mor, and Thompson, 1992; Sowell, 1995**). Although such evaluation plays an important role in quality assurance and program improvement (**Donabedian, 1980; Donabedian, 1982**), it does not provide adequate justification for program continuance. This inability to substantiate basic program effectiveness is particularly troubling given the level of funding focused on case management and the constraints faced by the health care system as a whole. The paucity of outcomes research on case management has been recognized by the Agency for Health Care Policy and Research (AHCPR), the Health Resources and Services Administration (HRSA), and the National AIDS Fund (formerly the National Community AIDS Partnership). In a joint statement, these agencies recently identified case management as one of nine priority areas for HIV research (**Shulman, 1996**).

This paper focuses on the issues encountered in evaluating the impact of HIV case management, with particular emphasis on the ‘nuts and bolts’ of examining any resulting health care cost savings. The cost issue deserves special and detailed attention because it represents a crucial policy concern,

² Both **Sowell** and colleagues (**1992**) and Twyman and Libbus (1994) examined the health care resource use of AIDS case managed individuals compared to non-case managed individuals. Neither research team found a significant difference between groups in the number of inpatient hospital days experienced. **Sowell et al.**, however, concluded that hospital costs were lower for the case managed group and that their life expectancy was significantly longer. Although **Sowell** briefly mentions that hospital factors, versus the effects of case management, could be responsible for this discrepancy, this potential confounding factor needs closer scrutiny.

on which little has been written, and because its evaluation presents major research challenges.

Introduction

This paper begins with a brief discussion of cost-benefit and cost-effectiveness analyses and their potential application to case management evaluation. Second, it examines the importance and challenges involved in constructing a non-case managed control group against which to compare case management outcomes. Third, a discussion of specific approaches for assessing the impact of case management on health care costs is presented. This includes a review of possible data sources, their limitations, and data management concerns. Fourth, issues associated with examining a range of non-cost related case management outcomes are addressed in a cursory fashion. Lastly, ideas for future research are outlined.

In addition to a knowledge of the literature, the authors bring practical experience to bear on these topics as a result of their participation in one or both of the following projects (as well as work on additional independent endeavors): an evaluation of AIDS Institute-funded case management services in New York City³ and a longitudinal comparison of inpatient resource utilization between PWAs cared for in Department of Veterans Affairs (VA) Hospitals and non-federal hospitals in California and New York⁴. When useful for illustrative purposes, examples from these two projects (still in progress) are presented.

³ Susan Lehrman and Daniel Gentry are principal investigator and co-investigator on this project, which is funded by the New York State Department of Health's AIDS Institute. Edward Waltz and John Fleishman are consultants on this project. Dependent variables of interest include referral success, client satisfaction, client compliance with mutually agreed upon case management activities, duplication of case management services, and health care costs.

⁴ Susan Lehrman, Edward Waltz, John O'Donnell, and Joseph Englehardt are jointly involved in this project. Note that this study does not examine case managed versus **non**-case managed PWAs, but instead looks at inpatient resource utilization and cost approximations among different systems of care. Despite this limitation, many of the challenges faced are applicable to the evaluation of case management programs.

Mentioned throughout the paper are ‘contextual’ factors -- client demographics, disease stage, and others -- which influence the outcomes of case management. John Fleishman provides a thorough review of these factors elsewhere in this monograph (1998). One such contextual issue, however, deserves particular mention up front. Since case management does not occur in a vacuum, the availability and accessibility of referral services is a necessary prerequisite for effectiveness (Roberts, Severinsen, Kuehn, et al., 1992). The evaluation of both monetary and non-monetary case management outcomes, therefore, requires a simultaneous examination and understanding of the environment in which case management is provided. This underlying issue, while not discussed extensively in this paper, should be considered throughout.

Potentially relevant policy analysis tools

As the need to rationalize resource allocation has grown, cost-benefit analysis (CBA) and cost-effectiveness analysis (CEA) have received increasing attention in the health services literature. It is beyond the scope of this paper to review CBA or CEA in methodological detail and unnecessary given the abundance of literature reviews on these topics (Warner and Luce, 1982; Warner, 1989; Drummond, Stoddart, and Torrance, 1994). However, the challenges associated with the use of CBA and CEA in evaluating HIV case management deserve mention. A matrix approach to cost-effectiveness analysis (Warner, 1989) and a hybrid of CBA and CEA (Warner and Luce, 1982) are described and suggested as alternatives to more traditional cost-benefit or cost-effectiveness analyses for evaluating HIV case management.

In cost-effectiveness analysis, program consequences are measured in dollars spent per non-monetary unit of benefit. An example would be dollars spent for years of life saved or days of disability avoided. As a result, CEA sidesteps one of the major limitations of CBA -- the difficulty or undesirability of valuing important health outcomes in dollars and cents.

On the negative side, however, CEA, unlike CBA, does not permit a comparison of alternative resource use between programs with different objectives (unless they can be measured with a common metric); nor does CEA allow judgments about the inherent worth of a program. Rather, it facilitates a comparison of relative efficiency between two or more interventions with the same goals and outputs -- interventions that often are simply assumed, without benefit of actual analysis, to be cost-beneficial. Both of these negatives are problematic in the context of evaluating HIV case management.

Definitions of case management vary and a range of case management models exist. These include client-focused versus system-focused (sometimes referred to as the gatekeeper model of managed care) case management (Piette, Fleishman, Mor, and Thompson, 1992); psychosocial versus medical case management (Piette, Fleishman, Mor, and Dill, 1990; Indyk, Belville, Lachapelle, et al., 1993); and intensive versus non-intensive (sometimes referred to as 'core') case management (New York City Health Systems Agency, 1995). Due to the lack of process standards, considerable inconsistency occurs even within a given model (Rothman, 1991; Grier and Sowell, 1993; Sowell, 1995).

To varying extents, these models espouse different philosophies, have different goals, and serve different populations (Piette, et al., 1992; Benjamin, 1989; Sowell, 1995). Here is one example: while system-focused case management programs seek to decrease health care costs for the managed care system, client-focused case management attempts to increase access to care for the individual. Policy makers and providers might like to assume that these goals can be achieved simultaneously, but the reality is that they represent two very different perspectives (Tyman and Libbus, 1994; Benjamin, 1988) and produce outcomes that cannot be easily compared using the single summary measure typical of CEA.

And what of the more basic question: Is case management cost-beneficial in any of its manifestations? Cost-benefit analysis typically seeks to convert all benefits of a program into a single metric against which costs, expressed as dollars expended, can be compared. Program adoption/continuation depends on benefits of a program equaling, and preferably exceeding, the costs. Because the overall costs or benefits of a program are reduced to a single dollar amount, CBA allows a comparison of competing resource uses, even in situations in which goals and outputs are dissimilar.

The measurement of costs and benefits is fairly straightforward when a commodity is produced, subject to the laws of supply and demand and for which a dollar value can readily be obtained. Difficulties arise, however, when the output in question is not subject to normal market forces; in that case the dollar value of benefits requires estimation (Lambrinos and Papadakos, 1987).

In evaluating HIV case management, cost-benefit analysis would appear an important methodological precursor to CEA. However, difficult decisions arise as to which benefits are important for inclusion in the equation and

quantification of these benefits. For example, the benefits of HIV case management might include a decrease in health care dollars spent; a decrease in other social welfare expenditures; an increase in the percent of needed services accessed; an increase in the months of life **post-diagnosis**⁵; improvement in quality of life (which might include decreases in days of morbidity or disability and increased productivity, as well as less tangible factors); and increased client satisfaction with service coordination.

Which of these benefits should be included in the cost-benefit equation and how can they be blended into one measure and assigned a dollar value? Taking a close look at the challenges of measuring just one of these outcomes -- improved quality of life -- is edifying.

Typically, quality of life measures involve directly examining clinical or functional outcomes or assessing clients' self-perception of health. Important work specific to HIV recently has been published or presented in this area (Cleary, et al., 1993; Wachtel, et al., 1993; Bozette, et al., 1994; Avis, et al., 1995); however, further validation, refinement, and examination of the generalizability of these tools still is wanting. For example, the Cleary instrument was tested on only a small sample from a single geographic area. While Wachtel and colleagues believe their instrument (based on the Medical Outcomes Study Short Form Health Survey) has value for examining the cost-benefit of drug trials because of its sensitivity to symptoms, further work is needed before its benefits can be generalized to more broadly focused interventions, such as case management. Further, to be useful in cost-benefit analysis, such instruments ultimately must be refined to a single estimate of health status. This involves the added challenge of weighting a range of indicators in order to arrive at a summary figure (the approach taken by Bozzette and colleagues) and translating that figure into a dollar value. While several methodologies have been devised to overcome the obstacles presented in this example (for example, an examination of clients' "willingness-to-pay" for the benefits associated with a given service), controversy still surrounds their use (Warner and Luce, 1982).

Thus neither CBA nor CEA analysis in their pure versions provides an ideal method for evaluating outcomes associated with HIV case management.

⁵ It should be noted that increased life expectancy may have important cost implications since the longer a PWA lives, the **more health** care resources they consume.

Warner and Luce (1982) point out, however, that the distinctions between CBA and CEA need not be as sharp as the above description suggests. An amalgam of these two approaches may be particularly desirable in health-related program evaluation, in which the desire to capture the range of economic implications is strong but an unwillingness to place a dollar value on health outcomes prevails. Warner and Luce demonstrate and predict increasing usage of a combined cost-benefit/cost-effectiveness method (which they continue to label CEA). In this approach, the bottom line remains dollars per unit of health outcome but a range of indirect economic effects (be they debits or credits), ignored in more traditional CEA, are calculated into the cost side of the equation. Unfortunately, while this mixed analytic approach may be an improvement, it does not overcome the issues of noncomparability between models nor does it lend insights into which non-monetary outcomes should be examined or how multiple outcomes could be meaningfully combined into a single measure.

Another hybrid approach which at least partially addresses these issues is the cost-effectiveness matrix (Warner, 1989). Warner has pointed out that many health care programs, “have multiple outcomes that do not lend themselves neatly to being measured, weighted, and summed into a single index. In such instances, an alternative approach might be to array costs and outcomes in a matrix form.” For example, a cost-effectiveness matrix examining HIV case management could array some or all of the non-monetary benefits of case management across programs with common outcomes, along with a single summary dollar figure for each program (combining all monetary costs and benefits). Exhibit 1 below provides an example of how this approach could be structured. To be meaningful, such a comparison would need to be further adjusted for disease acuity and demographic characteristics of the populations served as well as for other contextual differences between programs. Because the basic efficacy of case management remains open to question, the inclusion of a non-case managed control group as part of the comparison is, when feasible, ideal.

The importance of a comparison group for evaluating HIV case management

Because clients typically self-select into case management, they may be very different from those who do not use case management services. Without an appropriate control group, measurements of case management effectiveness may partially reflect these differences in client characteristics, rather than the effects of the intervention.

Exhibit 1 Cost Effectiveness Analysis Matrix			
Program	Costs Per Client Per Year *	Days of Morbidity Per Year	Percent Needed Services Accessed Per Year
A	\$ 22,000 CM=\$ 2,000 HC=\$ 20,000	45	80
B	\$20,000 CM=\$ 2,000 HC=\$ 18,000	30	95
c	\$25,000 CM=\$ 3,000 HC=\$ 22,000	85	70
D non- case managed	\$ 22,000 CM=\$ 0 HC=\$ 22,000	60	68

* Health care costs plus the costs of providing case management
CM = Case management costs HC = Health care costs

A study using clinical trial design probably is the ideal solution to this problem. Unfortunately, this may not be easy to achieve due to costs and the ethical issues associated with denying case management services to individuals who might otherwise wish to use such services. Peter Messeri, who has conducted case management evaluations for the New York State Department of Health AIDS Institute, offers the following statement:

"Empirical studies that would be able to isolate the relationship between case management services and reduced medical costs or improved quality of life measures are all but impossible to conduct with the resources normally available for program evaluation. It is extremely expensive and logistically demanding to track a sizable cohort of clients and a matched set of controls for the long period over the course of HIV disease that would be required to validate long-term effects of community-based case management on lengthening the period of disease-free life and reducing the frequency and length of inpatient care." (Messeri et al., 1992).

Retrospective methods of comparison group selection are more feasible but have serious limitations. Using a retrospective approach, individuals who

have either opted not to participate in case management or who have not had the opportunity to make that choice would be recruited to form a comparison group. While there undoubtedly are large numbers of non-case managed PWAs, even in geographic areas with relatively extensive case management systems, locating these individuals is a daunting task. This is particularly true because they are likely to be individuals who, for varying reasons, are not well connected with HIV service providers.

Further, these individuals are likely to be less than ideal for comparison purposes. Those who have consciously decided not to participate in case management may be less (or more) severely ill or may have greater (or lesser) ability to access needed services on their own than of their case managed counterparts. Ideal candidates for such a comparison group probably are those on waiting lists for case management. However, even they may be, on average, at an earlier stage of disease progression than those already in case management. Additionally, not all areas of the country have case management waiting lists.

Addressing this issue in conjunction with the evaluation of AIDS Institute-funded case management services in New York City, the authors explored several retrospective approaches to constructing a comparison group since neither prospective selection nor the use of waiting lists was feasible. The solution – while not ideal – is to select a group of non-case managed controls from the Medicaid database, matched by disease stage and demographics to the study participants who are also Medicaid recipients. The health care expenditures for these two groups will then be compared. Several tools designed to measure HIV disease stage will be used in the matching process to help ensure the similarity of comparison and study groups.⁶

Comparison groups of individuals enrolled in different case management models (psychosocial versus medical models, for example) are inherently easier to construct than comparison groups consisting of case managed versus non-case managed individuals. Yet even comparisons between case management models may be stymied by differences in program goals and populations served (for example, the needs of male intravenous drug users

⁶ Unfortunately, lack of funding precludes interviewing these comparison individuals about such outcomes as service acquisition or satisfaction with services accessed. These are the types of questions which will be asked of case managed individuals included in the study.

may be very different from that of women with children). Further, they fail to address the crucial issue of whether case management really is more effective than no intervention at all.

Evaluating the **health care cost savings** associated with HIV case management

Calculating the costs of producing case management services

A first step in CBA, CEA, or a hybrid method, is determining the cost of providing the program or service so that this amount can later be deducted from or compared to any benefits. On the face of it, to estimate case management costs per client, the sum of funding for a given program initiative (at, for example, the State level) can simply be divided by the total number of individuals served. However, the number of clients served may be difficult to determine when examining large State or citywide programs. Further, the presence of multiple funding streams aimed at multiple program initiatives may make it difficult to isolate specific program costs. Lastly, this method fails to identify differences in costs at the agency level – differences which may be substantial (Messerli et al., 1992).

Although preferable, examining costs at the agency level presents its own challenges. Many agencies provide more than case management services to their clients, with labor and overhead not always clearly differentiated between programs. Although most agencies attempt to reflect such allocations in their budgeting process, many lack the requisite cost-accounting sophistication to successfully differentiate between various program expenses. Thus, either taking overall agency costs or program specific budgets and dividing by the number of clients served by that agency has limitations (Capitman, **Haskins**, and Bernstein, 1986).

The Capitman and Messeri studies, cited above, emphasize the importance of using more refined methods to calculate HIV case management costs and provide guidelines for employing these methods. Both studies point to major differences in costs across agencies – even when these agencies provide similar services in the same city and are financed by the same funding source. These differences are magnified when divergent types of agencies are examined in different geographic locations (Messerli et al., 1992; Capitman, **Haskins**, and Bernstein, 1986).

Once case management production costs are determined, the extent of health care cost savings (if any) can be assessed and entered into the **cost-benefit/cost-effectiveness** equation.

Important caveats for examining health care costs savings

Several caveats deserve mention prior to discussing the measurement of cost savings associated with providing case management services to **PWAs**. One stresses the importance of asking, “costs from whose perspective?” For example, costs incurred by a hospital in caring for an HIV patient may not be reflected in the Medicaid reimbursement to that hospital. Further, case management could result in increased costs outside of the health care domain. For example, persons receiving case management services may increase their utilization of public housing or legal aid services. Even if health-related costs could be shown to decrease, the total public burden might increase. Second, costs, charges, and levels of reimbursement, although often used interchangeably, are not valid substitutes for one another. Costs are what the provider organization actually expends in providing a service; charges are what that provider charges the client, third party payer, or both, for providing that service (assuming the service is not provided under a predetermined reimbursement contract); and reimbursement levels are what the third party payer actually pays for that service (Neumann, Suver, and Zelman, **1993**).

Lave and colleagues suggest that, “using list charges will overestimate both the social cost and the private cost of hospital and physicians services used in treating the condition.” (Lave, Pashos, Anderson, et al., 1994). If there were a uniform ratio between costs and charges across providers, the substitution of charges for costs might be a viable approach. However, evidence suggests that substantial variation exists in this ratio even within the same area. Sowell and colleagues (**1992**) found that charges for the same 10 HIV-related procedures varied by as much as 36 percent in five Georgia hospitals, although there was no indication that actual costs varied substantially.

The reputed discrepancy between hospital costs and reimbursements from publicly funded programs is a long-standing issue in this country. Lave and associates suggest that because, “reimbursement depends primarily on the fixed DRG payment [for Medicare patients], it does not reflect the resources used in treating a given patient.” Work by Kowal, Pal, and Rosner (1992) supports this contention. Comparing the inpatient costs of HIV care in one New York City hospital to the level of reimbursement mandated for that care by New York’s all-payer DRG reimbursement system, they found that allowed reimbursements covered only 64 percent of the hospital’s costs. Examining reimbursement more broadly, the National Association of Public

Hospitals reported in 1987 that revenues met only 51 percent of the costs of caring for HIV patients in metropolitan hospitals (Andrulis, 1989).⁷

Unfortunately, despite the desirability of examining costs, reimbursement levels and charges consistently are more available to the researcher than are costs and, as a result, frequently there is little option but to use them. Under these circumstances, it is incumbent upon the researcher to clearly define all terms employed, to explain any methods used in an attempt to create cost proxies, and to delineate clearly the limitations of the approach.

In the process of comparing estimates of lifetime AIDS costs, Scitovsky (1989) described several cost-related issues which go beyond concerns over whether costs, charges, or reimbursement levels are examined. According to Scitovsky, "[t]he comparability of these estimates is limited. They refer to different time periods and are in dollars of different years; some are limited to hospital costs while others refer to total costs; and some are in terms of costs while others are in terms of charges." (1989). It is important for the researcher to address, or at the least acknowledge, issues of cost comparability across time as well as the scope of costs examined in a given study.

One alternative to examining costs, which sidesteps some of the issues discussed above, is to utilize measures of health resource consumption (e.g., number of hospital admissions, lengths of stay, total bed days of care, emergency room visits). This was the approach taken by the authors in contrasting inpatient resource utilization between PWAs cared for in VA hospitals and non-federal hospitals in California and New York. In taking this approach, it must be remembered that the cost of producing a day of hospital care or other unit of service is not consistent across geographic areas or even within a given geographic area (American Hospital Association, 1994). Nor is cost consistent between days within a single hospitalization or between hospitalizations for the same individual. The first several days of care are generally more expensive than subsequent days. Kowal and colleagues found that the costs of inpatient care were higher on the initial hospitalization following an AIDS diagnoses than in later hospitalizations, possibly due to the intensity of testing on the first admission (1992).

⁷ While government reimbursement levels have historically been of more interest to policy makers than provider costs, concerns about cross-subsidization of public patients by private payers can no longer be ignored and, therefore, an assessment of actual costs should be pursued whenever possible either in lieu of, or in addition to, an examination of reimbursement levels.

Using primary data to assess health care cost savings

The remainder of this section addresses the use of secondary or administrative data to evaluate the cost savings associated with HIV case management. A brief discussion of primary data collection (here narrowly defined as collecting cost data directly from the client), however, is warranted. Direct client contact, via surveys or interviews, allows the researcher to access cost information that may not be available from secondary databases, especially administrative data sets, such as expenses for services not covered by third party payers. Beyond measuring out-of-pocket direct health care costs, primary data collection allows questioning of the client about personal opportunity costs, such as loss of revenue associated with family caregiving or the costs associated with lost economic productivity. Primary data collection also allows incorporation into the analytic model of a broader range of independent variables, such as measures of housing status or the availability of significant others, that are not typically available in administrative databases.

The negatives associated with primary data collection are obvious. Data collection is both expensive and time consuming. Patient cooperation may be difficult to obtain. Reliability and validity concerns arise from memory limitations or clients' lack of knowledge about charges that do not directly impact them (Aday, 1989). Further, with the possible exception of out-of-pocket expenses, delineating between costs, charges, and reimbursement levels may be particularly difficult for clients.

On balance, the collection of primary cost data from clients may be most realistic if three conditions exist simultaneously: if direct client contact already is part of the planned study, if the costs of interest are not reimbursed by third party payers, and if the costs were incurred relatively recently. Where possible, information taken directly from clients should be validated by a secondary data source (Aday, 1989).

Primary data collection could also involve seeking cost information directly from health care providers. The AIDS Cost and Services Utilization Survey (ACSUS) database is an example of this type of direct data collection (Berk, Maffeo, and Schur, 1994). Unfortunately, few researchers have the resources available to launch such a major undertaking.

Using administrative data to assess health care cost savings:

overview of administrative data bases, sources, and accessibility

Administrative databases⁸ offer the benefits of being reasonably available, more accurate than primary data for examining certain variables (such as third party payer reimbursement levels), and extensive (often covering the entire population of individuals in the system, not merely a sample of individuals in that system). However, the use of such data also presents limitations. While arguably easier to obtain than primary data, accessibility issues are nonetheless substantial. Reliability and validity issues, practical problems such as the need to merge multiple databases cross-sectionally and over time, concerns about comparability between data sets, and a lack of relevant variables also are concerns.

Perhaps the greatest limitation to using administrative data to evaluate HIV case management is the fact that information on HIV status and whether individuals are case managed rarely is included in the database. Therefore a first step in considering the use of such data is determining whether this information is available. Failing that, if the database contains unique, externally valid client identifiers (most likely social security or insurance identification numbers) these may allow it to be linked with another data set which does include case management or disease status information. Just as important is the need to ascertain whether these identifiers will be available to an independent researcher.

Additional limitations associated with using administrative databases are examined elsewhere in this paper. Other issues -- such as adjusting the data for disease stage and developing cost proxies, while not necessarily concerns limited to administrative databases -- are discussed below. First, however, examples of administrative data with potential use for HIV case management evaluation are listed, along with issues of accessibility. This listing is meant to be suggestive of the types of cost/charge/reimbursement and resource utilization data available rather than exhaustive. Since the authors are most knowledgeable about databases specific to New York, examples from that State predominate. However, in many instances comparable data exist in other States. Non-administrative secondary data sources, particularly those focused on HIV, also are mentioned.

The more comprehensive (here defined as covering the range of health care services a single PWA might access) and complete (here defined as covering a

⁸ Defined as gathered primarily for administrative, not research, purposes.

significant percentage of PWAs in the population) the database, the more useful it is for evaluating the health care cost implications of HIV case management. Third party payer databases -- such as Medicaid, Medicare, the VA database, and those of private insurers -- tend to be relatively comprehensive since they typically encompass inpatient and outpatient services as well as charge and reimbursement information.⁹ Unfortunately, they tend to be less than complete in terms of covering the entire AIDS population. Rather, each focuses on a particular segment of that population, raising generalizability issues. Further, since individuals may move among these payment systems, even summing across them is not necessarily valid because of the potential for double counting.

With 40 to 55 percent of PWAs enrolled in Medicaid, depending on the State, its records represent the most complete database available on the AIDS population (Fleishman and Mor, 1993; Andrews, Keyes, Fanning, and Kizer, 1991). This, coupled with its comprehensiveness, have made it a highly desirable source of information on the AIDS population -- a source that has been used in several influential cost studies (Andrews, Keyes, Fanning, and Kizer, 1991; Hay and Kizer, 1993 -- see Keyes, Andrews, and Mason, 1991, for information on building an AIDS research file using Medicaid data). The VA database, while covering significantly fewer individuals in each State than Medicaid, has the advantage of being the only nationwide population-based (i.e., not a sample) source of data on PWAs.¹⁰

Given that it takes two years for non-elderly PWAs to qualify for Medicare once deemed disabled, Medicare data, while comprehensive, does not cover an extensive portion of the AIDS population, most of whom are young or middle aged (Lave, Pashos, Anderson, et al., 1994)). On the other hand, since 10 percent of the AIDS population are 50 or older (Emlet, 1993) the utility of the Medicare database for HIV case management research should not be ruled out entirely. Private insurance offers another comprehensive data source which is often limited in completeness. Nonetheless, depending on the research question, private insurers may provide useful repositories of information. For example, looking at lifetime AIDS costs, Rodriguez and colleagues used data from two private insurers in Puerto Rico which, together, encompassed 35 percent of the overall insured population (1993).

⁹ An important limitation to bear in mind, however, is that none of these databases are totally comprehensive, since care received outside the system is not documented.

¹⁰ Approximately seven percent of PWAs receive VA care and the VA's share of HIV patients is growing rapidly (Peterson, 1992; Bennett, Adams, Bennett, et al., 1994).

Hospital discharge databases -- such as New York's Statewide Planning and Research Cooperative System (SPARCS) database, California's Office of Statewide Health Planning and Development (OSHPD) database, and Missouri's Patient Abstract System (PAS) -- provide individual level information on all patients admitted to hospitals in those States. Most other States have similar data collection programs, and an effort by AHCPR, the Healthcare Cost and Utilization Project-3 (HCUP-3), is underway to standardize the system nationwide (Roxanne Andrews, Personal Communication, 1995). Information typically available in such databases includes client demographics; date and source of admission; diagnoses and major procedures administered; lengths of hospital stay; expected source of payment; and total charges. Aside from this core information, States may collect additional data. For example, New York collects information on the number of days spent in intensive care and Missouri now collects data on hospital outpatient and emergency room use.

Since most of these databases are limited to inpatient care, they tend to be relatively complete" without being comprehensive. In 1988, Drummond and Davies claimed that focusing on inpatient care had led to a 10 percent underestimate of lifetime AIDS costs -- a rate which they predicted would rise as outpatient treatment modalities became increasingly available. The inpatient focus of these databases is particularly limiting for research on community-based case management, with its stated goal of encouraging outpatient care. They may, however, be more useful for examining savings related to hospital-based case management programs where the explicit goal is to ensure timely discharge to more appropriate levels of care.

A possible option for expanding the comprehensiveness of discharge databases, or other administrative databases, is to merge the information they provide with other sources of patient information. In New York State several databases are available which include such information. The AIDS Intervention Management System (AIMS), operated by the New York State Department of Health, contains data (including outpatient data) on all clients treated in designated AIDS centers (hospital-based sites designated by the

¹¹ For example, in combination, the OSHPD (California) and SPARCS (New York) databases include more than 40 percent of PWAs in the United States (New York State Department of Health, 1992; Centers for Disease Control and Prevention, 1994).

Department of Health AIDS Institute as specialized AIDS care centers). The AIDS Drug Assistance Program (ADAP) provides funds to help meet the prescription drug needs of the medically uninsured and under-insured who do not qualify for Medicaid. Although ADAP is not limited to New York, the New York program is particularly comprehensive, covering roughly 180 drugs as opposed to less than 10 in some States, and thus provides a rich database on prescription drug usage (Thomas Chestnut, Personal Communication, 1995). Yet another New York data source is the Minimum Data Set Plus (MDS+) which provides information on nursing home costs, including the costs of caring for PWAs. The Client Level Uniform Reporting System, piloted by HRSA in selected CARE Act Title I EMAs and Title II States, may hold promise for future research endeavors although it remains unclear whether these data will be gathered on a more widespread basis in the future.

Unfortunately, at least from an evaluation perspective, accessing these and other administrative databases is often challenging and sometimes impossible -- depending on such issues as who is sponsoring the research, the specific focus of the research, the resources available to reimburse the agency providing the data, and the level of data aggregation needed.

Accessing Medicaid data may be particularly difficult. Under a Federal ruling on the confidentiality of Medicaid AIDS data, researchers are required to demonstrate that use of the data will directly impact the administration or monitoring of the Medicaid Program (New York State Department of Social Services, 1995). This may place a heavy burden of proof on potential users.

The challenges of accessing other databases vary substantially depending on State and agency specific policies. For example, a relatively informal process is followed to acquire the public version of OSHPD (California) discharge data (this version contains scrambled social security numbers), while acquiring any SPARCS (New York) discharge data requires a more formal application and review process. For confidentiality reasons, accessing administrative data complete with externally usable client identifiers is uniformly difficult. Further, many of the databases simply do not code external identifiers. For example, a number of State discharge databases do not include social security numbers (Roxanne Andrews, Personal Communication, 1995).

Alternatives to directly accessing administrative data deserve exploration by the researcher. A researcher may choose to work collaboratively with the agency responsible for the database. In this case, the researcher enters into a

contract with the agency, increasing the agency's control and comfort level concerning confidentiality issues. A researcher may reimburse the agency to make necessary linkages between multiple databases or actually conduct analyses for the researcher based on his/her specifications. This allows the agency to purge the data set of confidential information prior to delivery while still meeting the researcher's needs. Since employees of the agency responsible for the database are likely to be most knowledgeable about data content and meaning, they may make particularly valuable research partners.

Secondary data sources not developed primarily for administrative purposes may also be of use to researchers. Since the information available in such data sets is typically collected for a specific research purpose, however, they often have limited utility for examining other research questions. For example, the ACSUS data set, while an extremely rich source of AIDS related information, lacks externally usable individual identifiers or even geographic identifiers and contains very little information on case management use.¹² Likewise the Multicenter AIDS Cohort Study (MACS) contains a wealth of information but fails to identify whether or not participants receive case management services (Lisa Jacobsen, Personal Communication, 1995).

Quality of administrative data bases

Questions about the accuracy of hospital discharge data and other administrative databases have spawned a considerable literature over the last decade (Kaufman, 1986; Iezzoni, 1990; Iezzoni, Daley, Heeren, et al., 1994; Jencks, Williams, and Kay, 1988; Romano and Mark, 1994). Researchers using administrative data must be aware of the inherent potential for errors of various types." In order to identify the extent of under-coding and

¹² The ACSUS survey asked clients whether they had contact with either of two types of case managers -- a home care case manager or a mental health case manager. These case managers were listed with other providers from either home health or mental health, and the client asked to identify whether he/she had been assisted by each provider on the list in turn. Given the cursory nature of the questioning, substantial detail is missing which might allow for a meaningful analysis of case management related outcomes (for example, the length of time of the case manager/client relationship or its intensity).

¹³ For example, in the case of diagnosis, a patient may not be diagnosed (under-detection), the diagnosis may be made correctly and not noted in the medical records (under-reporting), the diagnosis may be made correctly and entered correctly in the medical record but not entered in the administrative record (under-coding), the diagnosis may be made incorrectly (misdiagnosis), or the correct diagnosis may be entered incorrectly in the medical record or the administrative record (transcription error).

transcription errors in the data system, a statistically appropriate sample of medical records needs to be selected and reviewed. This is an expensive and time consuming task. Further, problems of under-detection, misdiagnosis, and under-reporting are difficult to ascertain even from medical record reviews.

Fortunately, many administrative databases have undergone reliability and validity checks by the accountable agency or by independent researchers, although not always for information specific to HIV. Given the high costs and logistical difficulties of conducting a full-fledged validation study, most researchers will need to utilize such studies to support their research proposal(s) and explore the limitations of their chosen **database**.¹⁴

Despite the lack of feasibility of conducting chart-based validation, researchers still can review their data for internal consistencies. Some of the approaches that the authors have taken, or plan to take, in terms of evaluating data quality in conjunction with the VA study include the following: In cases with multiple hospital admissions, the consistency of coding of demographic variables over those admissions will allow estimation of transcription error rates. In the case of consistency of HIV diagnosis, the authors will look back in time over each individual's case history to ascertain if HIV-specific co-morbidities were present in earlier hospital stays, absent an HIV diagnosis code. In the case of race, the race distributions in hospitals will be compared with other institutions serving the same ZIP codes for gross systematic errors." In terms of the coding of 'death,' each case will be checked over multiple hospitalizations to determine if more than one 'death' was reported or if subsequent hospital admissions followed a reported 'death.' Results of these and similar estimates of internal validity will be reported with the overall study results and their implications for the study findings will be examined.

Adjusting administrative data for severity of illness

The cost of medical care to treat an individual is associated with severity of illness. This relationship is particularly evident for HIV-related illness in

¹⁴ To cite several examples of validation studies conducted on the data sets used by the authors in their VA study: A recent article found good correspondence between SPARCS and the New York State Department of Health case registry (Muse, Smith and Mikl, 1992) and OSHPD conducted an external records-validation study in 1990 and found high rates of correspondence for most variables (Meux, Stich and Zack, 1990).

¹⁵ As an example of the kind of error that might be uncovered by this procedure, one New York hospital was found to apparently mis-code the race of all their Hispanic and Asian patients.

which symptomatology may range from infection with no clinical manifestation of disease, to profound physiological impairment (Hellinger, 1993). Thus, accurate comparisons of health care costs between individuals in competing case management models (or between individuals in case management versus no case management) can be confounded if severity of HIV illness remains unaccounted for in statistical models (Kelly, Ball, and Turner, **1989**; Andrews, Keyes, Fanning, and Fizer, **1991**; Ball and Turner, **1991**).

A number of tools drawing on clinical data such as vital signs, blood gas levels, and CD4+ counts, are available to measure and adjust for severity of illness.¹⁶ This information can typically only be obtained through a detailed audit of patients' medical records, an expensive and time-consuming process.¹⁷

Administrative databases, such as third party payer and discharge databases, while often containing diagnostic information, typically lack detailed clinical data such as CD4+ counts. The Severity Classification of AIDS Hospitalizations (SCAH-2) (Turner and Ball, 1995) offers a method to group HIV patients for severity of illness in the absence of detailed clinical indicators. The SCAH-2 is an automated system designed specifically for use with administrative data on hospitalized HIV patients and should not be applied indiscriminately to non-hospital data. It categorizes patients into one of three progressive illness stages, and within stages into a total of 20 possible sub-stages. The SCAH-2 was developed and validated using SPARCS discharge abstracts, and has been used in the comparison of patterns of HIV care between treatment settings (Kelly, Ball, and Turner, **1989**; Ball and Turner, **1991**). The SCAH-2 likewise will be used by the authors in their New York City and VA studies.

¹⁶ Examples include the Walter Reed Staging Classification system (Redfield, Wright, and Tramont, **1986**), The Computerized Severity Index (Horn, Sharkey, and Buckle, **1991**), and the World Health Organization Staging System (World Health Organization, 1990).

¹⁷ On the other extreme, some researchers classify HIV patients based solely on the presence of a few specific HIV-related comorbidities (Rothenberg, Woelfel, and Stoneburner, **1987**) or HIV risk groups (Andrews, Keyes, Fanning, and Kizer, **1991**) but make no attempt to group patients by relative severity of illness.

Intensive medical efforts immediately preceding death have been associated with particularly high health care costs. This is not a problem with population-based data or when large representative samples are used. With small and non-representative samples, however, it becomes a concern because the death of even a single individual can skew study results between cases and controls. Conversely, once death occurs, health care costs drop to zero. If death occurs early in the study period, results may be skewed in the opposite direction. Researchers have handled these problems in different ways. For example, they may limit the study to individuals currently living with HIV (although this fails to exclude those near death). This approach was taken by the authors in evaluating HIV case management in New York City. Researchers may use statistical adjustments (Ash, 1989) or they may only include those who have died, reconstructing their cases backward over a consistent time period (Sowell, Gueldner, Killeen, et al., 1992; Twyman and Libbus, 1994).

Developing cost proxies

Another possible adjustment when comparing the cost outcomes of case management is the conversion of charges, reimbursement levels, or resource use (bed days of care, for example) into cost approximations.

Several different methodologies can be used to adjust charges to serve as proxies for costs; however, each has inherent limitations (Lave et al., 1994). A facility's overall cost-to-charge ratio can be computed from Medicare's Health Care Provider Cost Report Information System, and can then be multiplied by charges to reach a cost estimate. This method, predicated on the assumption that the ratio of costs to charges is consistent across the organization, may not be uniformly valid. Alternatively, Lave et al. outline steps for adjusting charge data at the department level. This effort, however, is cumbersome and often stymied by missing departmental information and extreme outliers.

In the authors' VA study, they face the challenge of approximating costs based on resource utilization. Cost estimates will first be calculated based on the mean cost of a day of HIV hospitalization in California or New York, multiplied by the bed days of care derived from the administrative databases for each of those two States (see Hellinger, 1993).¹⁸ The authors will also employ a more sophisticated conversion methodology using a system of 12 HIV-specific DRGs developed by the New York State Department of

¹⁸ Estimating VA costs will be more difficult given the budgeting methodology used to fund VA hospitals.

Health. By grouping study patients into these **12** categories and weighting each State's average hospital costs by the DRG-specific Service Intensity Weights, cost estimates will be adjusted for differences in case mix between States.

Other issues related to using administrative data

The use of administrative databases to evaluate HIV case management may involve the need to join multiple data sets in order to expand the sample. When linking databases, considerable attention should be given to assure that like variables from different sources are re-coded, when necessary, to achieve correspondence. Coding anomalies have been identified between the VA, OSHPD, and SPARCS databases by the authors involved in the VA study.¹⁹ Because administrative databases and other secondary data sources were created for specific purposes, the variables available for use in HIV case management evaluation often are limited. Merging data sets is one option for expanding the availability of data fields. Another is to look for proxies within the fields that are available. For example, in the authors' VA study, hospital discharge data fail to contain information on route of HIV transmission. Intravenous drug use (coded as an ICD-9 diagnosis code) - the only relevant variable available pertaining to risk group membership - was used as a **proxy**.²⁰ It must be acknowledged that variable limitations in administrative databases, although at times surmountable, often are realities that inadvertently narrow the scope of a study.

¹⁹ To systematically manage such problems, data dictionaries should be developed for each data system and, when a lack of correspondence is identified, both the old and new coding categories should be recorded/ Systematic decision rules should be developed and used to govern the recoding process whenever possible. Note that a similar procedure may be necessary when the same database is used over time, since definitions and descriptions of variables often change.

²⁰ Another example from the authors' VA study may be informative. No direct measure of socioeconomic status (SES) was available in any of the three databases used (a widespread problem with hospital discharge data). Since health status and service characteristics are frequently closely associated with SES (Wolinski, Coe, Mossely, et al., 1985; Pappas, Queen, Hadden, et al., 1993), a proxy measure for each was needed. OSHPD and SPARCS included data on expected source of financial reimbursement for the hospitalization. Records identified as 'Medicaid' or 'Self-payment' (i.e., no health insurance coverage) were categorized as 'Low SES'; all other records with non-missing values were coded as 'Other SES'. In the VA database, individuals classified as eligible for 'Non-service Related Benefits' (which requires passing a means test) were coded as 'Low SES'; others were categorized as 'Other SES'.

To evaluate the health care cost implications of case management, the time frame in which cost/charge/reimbursement information is captured must match the time frame in which case management was provided. Further, the duration of time in case management needs to be sufficient for its impact to become **manifest**.²¹ This suggests the need to examine multiple years of administrative data. This is relatively easy when the database includes an internally consistent individual identifier, such as scrambled social security numbers in the OSHPD database. It is more challenging when such an identifier is not available.**

Once usable health care cost data have been accessed and processed and the cost of actually producing case management services calculated, the **non-monetary** outcomes of case management need to be assessed and entered into the overall cost-benefit/cost-effectiveness equation.

Evaluating **non-cost** related case management **outcomes**

This important topic is saved for last and covered briefly because it has received more extensive (although arguably still insufficient) coverage in the literature, not because it lacks importance. The intent of this section is not to provide a comprehensive discussion of the subject, but rather to reflect on several specific issues which have surfaced in the course of the authors' own evaluation efforts.

Identifying the non-monetary benefits of HIV case management typically requires primary data collection. Some of the difficulties involved in such a task (confidentiality concerns, expense, lack of measurement tools, and client

²¹ A related issue is the portion of time spent in case management that is examined in the evaluation. Logic suggest that the initial months of case management may be more service acquisition intensive than subsequent months.

²² For example, until 1994 the only individual identifiers routinely available in the SPARCS database were the patient's medical record number (uniquely assigned to individuals only when hospitalized within the same facility) and insurance codes. In most cases, the latter do uniquely identify individuals; but the field includes various typographical vagaries, such as spaces embedded inappropriately within number sequences and block translocations (e.g., 'NYS 1234' in one record, '1234 NYS' in the next), that necessitate considerable manual processing. This information has been used successfully to create longitudinal records for individuals with HIV infection (Kaufman, Gradau, Schmidt, et al., 1990), but the process is far more time-consuming than direct linkages with scrambled social security numbers.

inconvenience) have been outlined above and will not be repeated here. It does deserve mention, however, that the source of primary data most often examined in HIV case management evaluation -- the case management chart -- may be insufficient to answer many important outcome questions.

Researchers have found charts to be incomplete and difficult to interpret (Piette, Fleishman, Mor, and Thompson, 1992). Further, they lack information that only the clients may be privy to, such as level of satisfaction with the case management process or the quality of life experienced. Thus, in order to adequately reconstruct a given case, interviews with the case manager, the client, and possibly other service providers (for example, other case managers working with the client or representatives from other agencies) may be necessary. Exhibit 2 suggests a methodology for this reconstruction process. Exhibits 3 and 4 when viewed together, demonstrate the depth of questioning which can be achieved using the methodology outlined in Exhibit 2.

Fortunately, as case management data collection becomes more systematic (as could potentially occur through HRSA's Client Level Uniform Reporting System) an increasing amount of outcome data, at least in terms of client success in accessing services, may become available to researchers in an automated format. Other outcome information -- judgements about quality of life, for example -- will remain difficult to obtain and continue to require extensive primary data collection efforts until changes are made to the URS or other systematic data collection tools are implemented. The importance of, and methodological challenges associated with, measuring such outcomes has been alluded to earlier.

It should be emphasized that the need for a control group applies not only to examining the health care cost implications of case management but equally to examining non-monetary outcomes. For example, although **pre-**intervention/ post-intervention analysis can be used to assess quality of life relative to some types of interventions, such an approach is meaningless for evaluating HIV case management, where the effect of the disease is relentless yet fluctuating. Likewise, increased life expectancy can only be adequately measured by comparing case managed to non-case managed individuals.

Exhibit 2: Flow Diagram for Construction of Case Management Histories

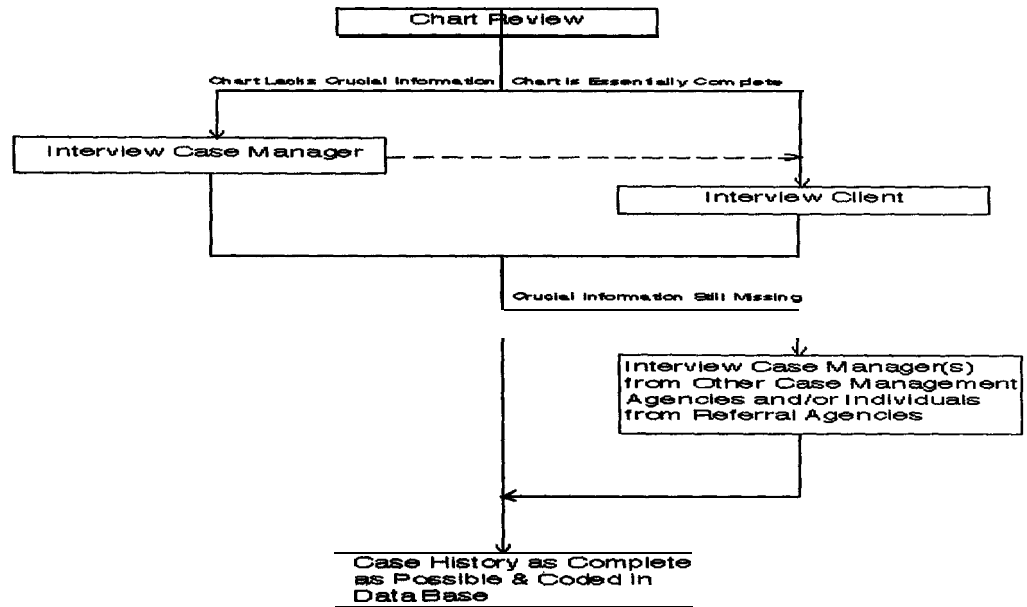


Exhibit 3: Questions Regarding Case Management Referral Success Which Can be Examined Using Exhibit 2 Methodology

For Each Client Referral Need, Was the:

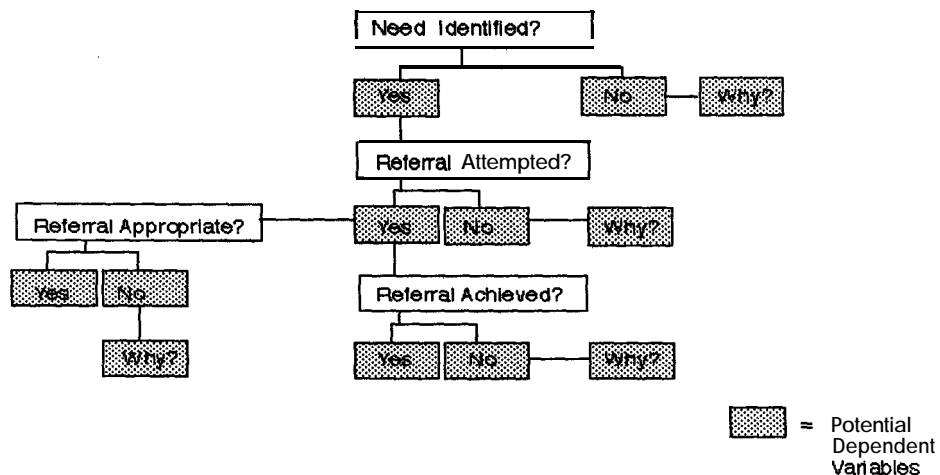


Exhibit 4 Sources of Information for Answering Case Management Research Questions					
Research Question for Each Need Identified	Chart Review	Client Interview	Case Manager Interview	Variable	Comments
Was referral need identified?	X	X		Number of needs identified by client not in chart	Measured by matching client response to chart information
If no, why? (Remaining questions moot).		X		Explanatory categories	Create categories based on exploratory interviews
Was referral attempted for identified need?	X	X	X	Percent of referrals needed but not attempted	
If no, why? (Remaining questions moot.)	X	X	X	Explanatory categories	Create categories based on exploratory interviews
Was referral appropriate to need?		X		Percent of referrals client considered not appropriate	
If no, why?		X		Explanatory categories	Create categories based on exploratory interviews
Was referral achieved?	X	X	X	Percent of referrals achieved	
If no, why?	X	X	X	Explanatory categories	Create categories based on exploratory interviews

Conclusions and research implications

Evaluating HIV case management requires analyzing the full range of outcomes (monetary and non-monetary) against the costs of providing the

service. Thus all cost and benefit issues discussed above must be brought together in one coordinated effort if impact is to be adequately assessed.

Ideally, such an effort should be undertaken in the context of a longitudinal, prospective, controlled, randomized study of sufficient length to capture the range of potential case management impacts. This is not a minor undertaking nor an inexpensive proposal. Given the current level of reimbursement for case management, however, it may well be essential. Further, it is not an effort that is within the reach of most States or a small team of researchers. Rather, it will require major support and input from experts who can measure all the outcomes associated with case management as well as those skilled in cost-benefit/cost-effectiveness analyses.

Simultaneously and in tandem, efforts need to be made to refine and validate quality of life measures and measures of other difficult to quantify case management outcomes. (Consideration should then be given to incorporating these measures into HRSA's Client Level Uniform Reporting System to facilitate ongoing evaluation as treatment modalities and the service environment evolve).

Lastly, these efforts need to occur expeditiously. States, as well as the Federal Government, increasingly face budget shortfalls and are looking for programs to trim or eliminate. Under these conditions, HIV case management will be vulnerable to cost-benefit/cost-effectiveness scrutiny and compared to competing program initiatives. Unless researchers are ready with outcome-oriented evaluation results, gathered through well-designed research initiatives, HIV case management funding may be jeopardized without benefit of the fair hearing it deserves.

References

Acquired immune deficiency syndrome (AIDS): interim proposal for a WHO staging system for HIV infection and disease. *Weekly Epidemiological Record* 65:221-228, 1990.

Aday, L. *Designing and Conducting Health Surveys*. San Francisco: Jossey-Bass, 1989.

American Hospital Association, *AHA Hospital Statistics, 1993-94 Edition*, 1994.

Andrews, R., Agency for Health Care Policy Research, Personal Communication, August 1995.

Andrews, R., Keyes, M., Fanning, T., Kizer, K. Lifetime Medicaid service utilization and expenditures for AIDS in New York and California. *Journal of Acquired Immune Deficiency Syndromes* 4(10):1046-1058, 1991.

Andrulis, D. *Crisis at the Front Line. The Effects of AIDS on Public Hospitals.* New York: Priority Press Publications, 1989.

Ash, A., Porell, F., Gruenberg, L., et al. Adjusting Medicare capitation payments using prior hospitalization data. *Health Care Finance Review* 6(1):27-38, 1985.

Avis, E., Smith K., Mayer, K, Swislow, L. The development of the MQOL-HIV: A quality of life instrument for persons with HIV. Presented at the American Public Health Conference in San Diego, 1995.

Ball, J. and Turner, B. *AIDS in US Hospitals 1986-1987: A National Perspective.* Agency for Health Care Policy and Research, publication No 91-0015. Hospitals Studies Program Research Note 15, 1991.

Ball, J. and Turner, B., *Version 2, Severity Classification of AIDS Hospitalizations, User's Guide, 1995.*

Benjamin, A. Long-term care and AIDS: perspectives from experience with the elderly. *Millbank Quarterly* 66(3):406-411, 1988.

Benjamin, A. Perspectives on a continuum of care for persons with HIV illness. *Medical Care Review* 46(4):411-437, 1989.

Bennett, C., Adams, J., Bennett, R., et al. The learning curve for AIDS-related pneumocystis carinii pneumonia: experience from 3,981 cases in Veterans Affairs hospitals 1987-1991. *Journal of Acquired Immune Deficiency Syndromes* 1;8(4):373-378, 1994.

Bozzette, S., Hays, R., Berry, S., Kanouse, D. A perceived health index for use in persons with advanced HIV disease: derivation, reliability, and validity. *Medical Care* 32(7):716-731, 1994.

Capitman, J., Haskin, B., Bernstein, J. Case management approaches in coordinated community-oriented long-term care demonstrations. *The Gerontologist* 26(n):398-404, 1986.

Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report*. 1994.

Chestnut, T., New York State Department of Health AIDS Institute, Personal Communication, August, 1995.

Cleary, P., Fowler, F., Meissman, J., et al. Health-related quality of life in persons with acquired immune deficiency syndrome. *Medical Care* 31(7):569-578, 1993

Donabedian, A. Explorations in Quality Assessment and Monitoring. Ann Arbor: Health Administration Press, Vol I, 1980.

Donabedian, A. Explorations in Quality Assessment and Monitoring. Ann Arbor: Health Administration Press, Vol II, 1982.

Drummond, M. and Davies, L. Treating AIDS: the economic issues. *Health Policy* 10:1-19, 1988.

Drummond, M., Stoddart, G., Torrance G. *Methods for the Economic Evaluation of Health Care Programmes*. Oxford: Oxford University Press, 1994.

Emlet, C. Service utilization among older people with AIDS. *Journal of Case Management* 2(4):119-124, 1993.

Fleishman, J. *Research Design Issues in Evaluating the Outcomes of Case Management for Persons with HIV*

Fleishman, J., Mor, V., Piette, J. AIDS case management: the client's perspective. *Health Services Research* 26(4):447-470, 1991.

Fleishman, J. and Mor, V. Insurance status among people with AIDS: relationships with sociodemographic characteristics and service use. *Inquiry* 30(Summer):180-188, 1993.

Fox, D. The cost of AIDS from conjecture to research. *AIDS and Public Policy Journal* 2:25-27, 1987.

Franklin, J., Solovits, B., Mason, M., Clemons, J., Miller, G. An Evaluation of Case Management. *American Journal of Public Health* 77(6):674-678, 1987.

Crier, J. and Sowell, R. Standards and evaluation in community-based case management. *Journal of the Association of Nurses in AIDS Care* 4(1):32-33, 1993.

Hay, J. and Kizer, K. Medi-Cal expenditures for persons with AIDS. *AIDS and Public Policy Journal* 8(2):91-102, 1993.

Hellinger, F. The lifetime cost of treating a person with HIV. *Journal of the American Medical Association* 270(4):474-478, 1993.

Horn, S., Sharkey, I?, Buckle, J. The relationship between severity of illness and hospital length of stay and mortality. *Medical Care* 29(4):305-317, 1991.

Hughes, S. Apples and oranges? A review of evaluations of community based long-term care. *Health Services Research* 20(4):461-468, 1985.

Iezzoni, L. Using administrative data to assess the quality of hospital care. *International Journal of Quality Assessment in Health Care* 9:272-281, 1990.

Iezzoni, L., Daley, J., Heeren, T., et al. Identifying complications of care using administrative data. *Medical Care* 32(7):700-715, 1994.

Indyk, D., Belville, R., Lachapelle, S., et al. A community-based approach to HIV case management: systematizing the unmanageable. *Social Work* 38:380-387, 1993.

Jacobsen, Johns Hospkins University, School of Public Health, Personal Communication, 1995.

Jencks, S., Williams, D., Kay, T. Assessing hospital-associated deaths from discharge data. *Journal of the American Medical Association* 260(15):2240-2246, 1988.

Kaufman, G. *The Accuracy of the Expected Primary Source of Reimbursement as Reported by New York State Hospitals*. Statewide Planning and Research Cooperative System, New York State Department of Health, 1986.

Kaufman, G., Grabau, J., Schmidt, E., Han, Y. HIV-infected hospital patients in New York State – the development of longitudinal information from a hospital discharge data system. *New York State Journal of Medicine* (May):238-242, 1990.

Kelly, J., Ball, J., Turner, B. Duration and costs of AIDS hospitalization in New York. *Medical Care* 27(12):1085-1098, 1989.

Kemper, P. The evaluation of the national long-term care demonstration: overview of the findings. *Health Services Research* 23(1):161-174, 1988.

Keyes, M., Andrews, R., Mason, M. A methodology for building an AIDS research file using Medicaid claims and administrative data bases. *Journal of AIDS* 4:1015-1024, 1991.

Kowal, S., Pal, S., Rosner, F. Costs, revenue and profit/loss patterns for HIV-seropositive patients in a municipal New York city hospital. *AIDS Patient Care* 6(6):278-284, 1992.

Lambrinos, J., Papadakos, I?. An introduction to the analysis of risks, costs, and benefits in critical care. In: Fein, I., Strosberg, M., ed. *Managing the Critical Care Unit*. Rockville: Aspen Publishers, Inc., 1987.

Lave, J., Pashos, C., Anderson, G., et al. Costing medical care: using Medicare administrative data. *Medical Care* 32(7):JS77-JS89, 1994.

Marconi, K., Rundall, T., Gentry, D., et al. The organization and availability of HIV-related services in Baltimore, MD and Oakland, CA. *AIDS and Public Policy* 9(4):173, 1994.

Messeri, P., Glied, S., Howard, J., Kennedy, G. *Community Services Program Case Management for HIV Clients: an Analysis of its Functions, Cost and Effectiveness*. New York State Department of Health, AIDS Institute, 1992, unpublished.

Meux, E., Stith S., Zack, A. *Report of Results from the OSHPD Reabstracting Project: an Evaluation of the Reliability of Selected Patient Discharge Data July through December, 1988*. Office of Statewide Planning and Development, State of California, 1990.

Mor, V., Piette, J., Fleishman, J. Community-based case management for persons with AIDS. *Health Affairs* (Winter):139-153, 1989.

Muse, A., Smith, P., Mikl, J. The quality of computerized hospital discharge data. *American Journal of Public Health* 82:1044, 1992.

Neumann, B., Suver, J., and Zelman, W. *Financial Management*. Dubuque: Kendall/Hunt Publishing Co., 1993.

New York City Health Systems Agency. *Interim HIV/AIDS Strategic Plan Volume II, 1995*.

New York State Department of Health AIDS Institute. *AIDS in New York State. 1992*.

New York State Department of Social Services. *Data Exchange Application. 1995*.

O'Brien, B., Drummond, M., Labelle, R., Willan, A. In search of power and significance: issues in the design and analysis of stochastic cost-effectiveness studies in health care. *Medical Care* 32(2):150-163, 1994.

Pappas, G., Queen, S., Hadden, W., et al.. The increasing disparity in mortality between socioeconomic groups in the United States, 1960-1986. New *England Journal of Medicine* 329:103-109, 1993.

Peterson, M. VHA's AIDS caseload mirrors that of nation. U.S. *Medicine* 4-5, 1992.

Piette, J., Fleishman, J., Mor, V., Dill, A. A comparison of hospital and community case management programs for persons with AIDS. *Medical Care* 28(8):746-755, 1990.

Piette, J., Fleishman, J., Mor, V., Thompson, B. The structure and process of AIDS case management. *Health and Social Work* 17(1):47-56, 1992.

Redfield, R., Wright, D., Tramont, E. The Walter-Reed staging classification for HTLV-III/LAV infection. New *England journal of Medicine* 3 14: 13 1-132, 1986.

Roberts, C., Severinsen, C., Kuehn, C., et al. Obstacles to effective case management with AIDS patients: the clinician's perspective. *Social Work in Health Care* 17(2):27-40, 1992.

Rodriguez, M., Garcia, J., Lopez, J., Figueroa, C. AIDS cost monitoring as a tool for policy making. *AIDS Patient Care* 7(2):88-97, 1993.

Romano, I?., Mark, D. Bias in the coding of hospital discharge data and its implications for quality assessment. *Medical Care* 266(19):81-90, 1994.

Rothenberg, R., Woelfel, M., Stoneburner, R., et al. Survival with the acquired immune deficiency syndrome. *New England Journal of Medicine* 317:1297-1302, 1987.

Rothman, J. A model of case management: toward empirically based practice. *Social Work* 36(6):520-528, 1991.

Ruchlin, H., Morris, J., Gutkin, C., Sherwood S. *Expenditures for Institutional and Community-based Services by a Cross-section of Elderly Living in the Community*. Hebrew Rehabilitation Center for the Aged, 1987.

Scitovsky, A. Studying the cost of HIV-related illnesses: reflections on the moving target. *The Millbank Quarterly* 67(2):318-344, 1989.

Shulman, L. HIV/AIDS case management: a contextual view. Introduction to Working Group Meeting on Developing a Research and Evaluation Agenda for HIV/AIDS Case Management. October 5-6, 1995. Washington, D.C.

Sowell, R., Gueldner, S., Killeen, M., et al. Impact of case management on hospital charges of PWAs in Georgia. *Journal of the Association of Nurses in AIDS Care* 3(2):24-31, 1992.

Sowell, R. Community-based HIV case management: challenges and opportunities. *Journal of the Association of Nurses in AIDS Care* 6(2):33-40, 1995.

Turner, B., Kelly, J., Ball, J. A severity classification system for AIDS hospitalizations. *Medical Care* 27(4):423-437, 1989.

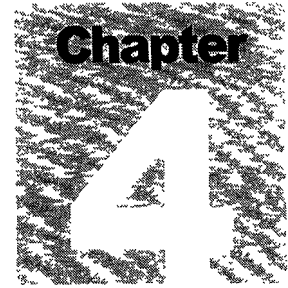
Twyman, D., Libbus, M. Case-management of AIDS clients as a predictor of total inpatient hospital days. *Public Health Nursing* 11(6):406-411, 1994.

Wachtel, T., Piette, J., Mor, V., et al. Quality of life in persons with human immunodeficiency virus infection: measurement of medical outcomes study instrument. ***Annals of Internal Medicine*** 116:129-137, 1992.

Warner, K., Luce, B. ***Cost-Benefit and Cost-Effectiveness Analysis in Health Care***. Ann Arbor: Health Administration Press, 1982.

Warner, K. Issues in cost effectiveness of health care. ***Journal of Public Dentistry*** 49(5):272-278, 1989.

Wolinski, F., Coe, R., Mosely II, R., Homan, S. Veterans' and nonveterans' use of health services. ***Medical Care*** 23(12):1358-1371, 1985.



The Political Economy of HIV Case Management

*Martin Nacman DSW**

The HIV epidemic exists in a health care environment that resembles an organizational jungle. In this jungle of episodic, discontinuous, often dysfunctional, and increasingly rationed resources, there has been a constant evolution of HIV disease with a broadening of the populations and risk behavior groups affected and infected. The populations in which the disease evolved seem generally irrelevant, except from an epidemiological perspective. HIV disease now is part of the human condition in most of the world and has spread by various routes to many segments of the human population.

At the same time, new medical, education, and prevention technologies have been regularly introduced in the U.S.. Many of these technologies are unproven but show promise of stemming the spread of the disease. HIV has forced the development of new organizational structures and care techniques that have had a rapid impact on health care services and financing. During the period that HIV was initially evolving in the U.S., an era of cost controls and resource rationing was introduced. The financing of health care became ever more chaotic and the concept of managed care in the for-profit and public sectors was introduced and expanded.

Case management seeks to provide a means of coordinating and facilitating access to and use of needed services in a fragmented environment. In response to the epidemic, case management techniques began mutating at a much faster rate than usual. This is not surprising because responses to HIV had to be both pragmatic and political as the epidemic spread into new locales

*Dr. Nacman, the retired director of social work at the University of Rochester Medical Center, is a consultant.

throughout the United States. Health care organizations have become very competitive, with each group striving to increase market share and financial domination of the health care environment. What effect cost controls and managed care have on services for people with HIV disease is only now becoming clearer.

Case Management

Case management, which existed under a variety of different nomenclatures for several years was included as a service under the Medicaid Waivers of the Omnibus Budget Reconciliation Act (OBRA) of **1981**. In 1984, the New York State Health Planning Council, concerned with facilitating hospital discharge of the elderly, developed a system of continuous care with case managers available to patients before, during, and after hospitalization (Baker and McCormack, 1984). This model was later applied to HIV programs. What has been termed the “San Francisco model” for persons with HIV provided a formal, centralized case management system. Over time, throughout the country various health and welfare organizations have experimented different forms of case management to meet the needs of their patients and communities (Martin, 1989).

The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) allowed States to provide case management for target population groups. In 1986, the Robert Wood Johnson Foundation and the Health Resources and Services Administration (HRSA) separately provided funding for multi-year demonstration projects to develop systems for people with HIV that included case management (Spitz, 1987). Greater emphasis on case management was evident in 1988 as a result of additional HRSA funding designed to increase access to care (Harder+Kibbe, 1991).

The case management models and service techniques for HIV that have emerged have been influenced by all of the governmental, social, ethnic, economic, and medical changes that have taken place since the HIV epidemic began. One set of changes specifically relates to the evolution of the HIV epidemic while another is in response to the changes that have taken place in health care delivery (addressed below).

Originally the case manager was directed by the physician to maximize positive outcomes for the client/patient. The functions and activities undertaken by the case manager included intake, assessment, service planning, referral, system linkage, coordination, counseling, and monitoring (Nacman, 1990). The goals included maximizing access and utilization of

required services, and increasing client/patient satisfaction and stability (Mor, 1989). The clinical strategy emphasized self-help (Weil, 1985). More recently, cost containment was introduced as a goal.

It became obvious that to achieve optimal quality of care for people with HIV disease requires mobilization and utilization of a broad range of systems. These include housing, social services, legal assistance, a recreational plan, job counseling, and income maintenance. Expanded social supports that go beyond the traditional medical model are also needed. Case management must assume greater responsibility for establishing comprehensive community systems to assist people with HIV, particularly as their disease shifts from an acute to a chronic syndrome (Vladek, 1987).

The problems and obstacles associated with the effort to provide comprehensive, uninterrupted health and welfare services to sick people predates the HIV epidemic but continues to plague case managers. Inadequate reimbursement, lack of bilingual capacity, institutional rigidity, agency insulation, maldistribution of resources, and concerns about confidentiality are barriers to achieving collaboration in the community and expanding programs for people with HIV (McCarthy et al., 1992). To a large extent, it has been extremely difficult to achieve the degree of integration and interorganizational networking that is necessary to produce coordinated and continuous case management with high quality results (Cheh and Keyes, 1994; Ridgely and Willenburg, 1992).

We now are confronted with considerable ambiguity with respect to the sponsorship, purpose, goals, strategies, and scope of case management programs (Harder + Kibbe, 1991). Numerous case management models exist although there is little consensus about what case management is or who should provide these services ((Knickman et al., 1988, Spitz, 1987, Dennis et al., 1992). In part this situation appears to be the result of the relative newness of the AIDS epidemic and of the vast differences that exist in the background, culture, needs, attitudes, and societal position of the people affected by HIV (Harder + Kibbe, 1994).

In addition to the managed care (*capitated*) approach that will be discussed in the next section, many service models have been described:

- . client-centered (Kane, 1985);
- system-centered (Mohr, 1988);
- . broker (Kane, 1991);
- . purchase authority for public funds (Kane, 1991);

- insurance (Kane, 1991);
- fee-for-service (Kane, 1991);
- intra- or inter-oriented (Desimone, 1988);
- linkage (McCarthy et al., 1992);
- ⌚ time-limited short-term (Lidz et al., 1992);
- ⌚ co-joint outreach (field station) (Levy et al., 1992);
- ⌚ service broker/cognitive behavior (Falck et al., 1992);
- ⌚ empowerment (McMillen and Chenny, 1992);
- ⌚ centralized and decentralized (Schlenger et al., 1992);
- ⌚ telecommunications (Alemi, 1992); and
- coordination of care (Harder + Kibbe, 1994).

By the 1990s, it became apparent that considerable variation existed in the definition of case management roles and goals depending upon financing, organizational setting, service techniques, and program emphasis (Mor et al., 1989; Weil, 1995). How these various elements are organized and processed varies from setting to setting. Case management outcomes depend on client characteristics and needs, availability of resources, case manager competence and relationship to the employing agency or person, and the availability of resources (Harder + Kibbe, 1988).

Managed Care's Achievements, Problems, and Conflicts

Health policy prior to the 1970s incorrectly assumed that economic growth, at national and local levels, would cover the increasing cost of health care services. As a result, health care policy shifted to a cost control mode. The traditional health care hierarchies formed in the 1940s were challenged. Because they were considered unable or unwilling to control rising costs, new health care policies and programs emerged. These changes favored competition and cost control as an approach to counterbalance the rising cost of health services (Fox, 1986). Although many health care practitioners were concerned about this shift, it became politically advantageous to support health care reform.

In the 1980s and 1990s, the belief emerged that American medicine was ineffective and too costly. Payer-promulgated practice guidelines became legitimized (Tannenbaum, 1994). Supporters of managed care indict the existing medical reimbursement system because, in their opinion, it does not provide sufficient incentives to reduce the cost of health care. With political support they have implemented a series of actions designed to eliminate the

misuse of hospitalization, diagnostic and treatment procedures, medications, supplies, and equipment. The managed care approach emphasizes improvement of coordination and management of health care by placing the primary physician in a central decision-making position in accordance with the policies of the employing organization, serving as a gatekeeper to avoid coverage of “unwanted” clients; rationing care; providing preventive programs to reduce or eliminate future health problems; delivering outpatient services to reduce hospitalization; offering brief psychotherapy to replace extended treatment; **capitating** compensation; and requiring continuous utilization review based on payer-promulgated practice guidelines (Tannenbaum, **1994**; Mechanic, 1995).

The clinical path identifies the various case management activities that should be completed before discharge. Since it is acknowledged that a clinical path is not appropriate for all patients with a specific diagnosis, it has been necessary to employ “variance analysis” to identify exceptions to the defined path (Colone, 1993). The necessity to create these variance pathways reflects the number of factors that have to be considered in treating a patient and the necessity to individualize care even in a cost management operation.

Outcome research has been developed in an attempt to establish statistically sound relationships between medical and psychosocial interventions and patient outcomes. It has gained strong support as the favored technique for evaluating what works and what does not. Outcome research tells us what is true across cases; for individual cases, outcome research offers only what is probable but not certain to be true. While outcome studies point out what personnel are doing wrong, practice guidelines provide information on how to practice correctly (Tannenbaum, 1994).

Several factors need to be considered in outcome research:

- Is outcome defined in terms of short-term or long-term results?
- Is outcome defined in terms of physical gain alone or are psychosocial and economic factors taken into consideration?
- What level of outcome is acceptable?
- How much variance will be tolerated?
- What level of quality is appropriate?

Unfortunately, these questions will probably be answered as much by political determinations as by scientific inquiry. Although there is hope that outcome studies and clinical pathways will provide more certainty, chances are that uncertainty may not be eliminated and may even be exacerbated

(Beresford, 1991).

Managed care has gained wide acceptance as a method for integrating the financing and delivery of health care services with the promise of controlling costs and improving quality. There is, however, a paucity of scientific data to justify the degree of acceptance that it has received. When managed care was imposed on the case management model, it immediately produced a significant shift away from decisionmaking by way of the **patient-physician-professional staff** relationship to institutionally derived mandates (Rodwin, 1995).

As health care reform shifted to a cost-containment and competitive mode, it gave birth to a number of different types of provider networks (labeled managed care programs). These networks were challenged to create a system of rules and incentives that together would provide the necessary checks and balances to ensure efficient and high-quality health care at the least cost (Millman, 1995). Immediately, the question arises as to whether managed care can control costs without compromising quality (Kane, 1988). While cost savings and quality of care are not incompatible, it is essential to define, with a high degree of specificity, the quality of care that is expected in relation to the level of cost control and rationing that is imposed. Maintenance of quality of care depends, in part, on the level of cost savings and profit that a health care organization sets out to achieve.

Much of the current emphasis on controlling the utilization and cost of health seems logical, particularly to reduce hospitalizations, expensive procedures, medications, and supplies. Patients should be protected against unnecessary and invasive procedures. Preventive approaches may help to avoid more costly procedures and lessen physical and psychological damage at a later time. Savings derived from these approaches could be used to provide health care for those presently not receiving this type of assistance or to reduce insurance premiums.

On the other hand, cost control can be used to increase corporate profits and executive salaries. For **example**, for the third quarter of 1993, investor-owned health care companies are reported to have shown record earnings. The provider and service group jumped **41** percent in profits on a **24** percent increase in revenues (Lutz, 1994).

At present, the features of existing managed care plans differ considerably and heated debates continue to occur about their performance. Some reviewers define managed care as a strategy to control profitability and as an

incremental step to place health care under corporate dominance (Cornelius, 1994; Yarmolinsky, 1995). The opportunity for competition that has been touted by the for-profit segment of the health care industry and by some politicians as a means of reducing cost could be compromised.

Some studies have sought to determine the effectiveness of case management and managed care in improving access, achieving cost reductions, and improving quality. Harder+Kibbe (1991) concluded that most case management studies were too preliminary to contain adequate, dependable findings. Miller and Luft (1995) point out that the absence of reliable, comprehensive, health system behavioral models for accurately estimating managed care's and managed competition's impact on health expenditure growth is a major research obstacle. There is much conflicting data.

There are reports that case management and managed care programs provide coordination and continuity in an otherwise fragmented system (Henderson and Collard, 1988; Harder+Kibbe, 1994; Cheh and Keyes, 1994). Access appears to be easier to ascertain than either quality or cost achievements, and some evidence exists that case management increases access. A lack of consensus exists on the ability of case management to reduce costs. In fact, some studies indicate that the cost of case management services is not offset by reductions in the cost of other services (Kemper, 1988; Spitz, 1987; Brookmeyer and Frank, 1993).

Another report suggests that case management results in increased costs (Harder+Kibbe, 1991). One review of managed care studies suggests that savings are sometimes achieved by substituting less expensive forms of treatment for more expensive ones, particularly for those previously experiencing above-average expenditures. To that end, outpatient services replace hospitalization and group treatment replaces individual treatment. There are reports that savings from reducing hospitalization appear to be greater than the cost of providing additional out-patient service (Rapp and Chamberlain, 1985; Toth, 1988; Henderson and Collard, 1988). For example, decreased emergency department usage has been linked to increased availability of primary care physicians on a 24-hour, 7-day-a-week basis (Hurley et al., 1993).

On the other hand, it has been reported that savings in managed care organizations sometimes are achieved by shifting services and costs to other community agencies, patients, and their families (Mechanic, 1995; Klein and Thornton, 1994; McClinton, 1995). Some emergency departments (ED) have complained that increasingly managed care organizations deny claims for

appropriate ED care. The point is made that denial of payment for ED visits may save money for managed care organizations but leaves hospitals and patients responsible for thousands of dollars in medical bills (New York Times, **1995**). Aggressive billing of patients by hospitals may also explain lesser use of the ED by patients.

The Medicare risk program for managed care organizations and competitive health plans was designed to reduce health care costs and the choices of beneficiaries. The findings of a 5 year program study show that costs were actually higher in the managed care settings when compared to fee-for-service (FFI) programs. Although outcomes for managed care and FFIs were similar, there were some striking differences in some procedures that might raise questions. The lower level of service observed in managed care organizations appeared to be the result of eliminating discretionary services although it was not found to adversely affect outcome (Brown et al., 1993).

Witek (1994) concludes that while managed care covering Medicaid beneficiaries has produced some successes and probably has more potential, evidence of performance is inconclusive. The key problems limiting success include lack of physician participation, challenges inherent in serving high risk populations, lack of preventive and primary care, inability to encourage provider risk sharing, and poor monitoring systems.

A 1993 U.S. General Accounting Office report on Medicaid managed care found conflicting results concerning cost savings and drew no definite conclusions. Medicaid managed care provided slightly better access to care and appeared to provide equal quality to fee-for-service providers. The report concludes that measuring quality posed many problems and that quality measurements are less reliable than access measurements.

The Case Manager

Case managers function in a variety of organizational settings and with varying degrees of authority, autonomy, and constraints. Harder + Kibbe (1994) working with the National Community AIDS Partnership (now the National AIDS Fund) studied coordination of care for persons with HIV. The study concluded that case managers are faced by the constraints of public and private funding, intractable regulations, unresponsive workers, competition between service providers, lack of cultural-specific service organizations, and lack of competent services in rural areas. Enhanced community involvement was cited as essential to developing appropriate and adequate responses to the HIV epidemic.

Very little consistency appears to exist in the training and background of case managers. Some case managers are social workers, others are nurses, clergy, psychologists, counselors, or physicians. Others do not fit into any of the traditional vocational classifications. Educational backgrounds also vary considerably. Non-professionals frequently provide case management services without professional supervision. Some case managers are paid employees while others are volunteers. No governmental standards define qualifications for case managers, and increased attempts are made to downgrade qualifications. Mor et al.(1988) present preliminary information derived from their evaluation of the Robert Wood Johnson AIDS Health Services Program. The study observed increased caseloads without staff expansion. Caseloads varied from an average of 40 to 200. Increased caseloads led to both time and service constraints. In some instances volunteer services were introduced to cover less complex situations.

Cheh and Keyes (1994) found in a four-city study of Medicaid programs that, with one exception – Houston’s centralized training program – there was no standard skill set, educational level, training, or professional experience required of case managers. Quality and effectiveness varied considerably. In some sites there appeared to be an inadequate number or complete lack of case managers. In some communities, volunteers were providing an enormous amount of service in coordination with case managers but also outside of that system. Communication was found lacking among community organizations and their case managers. In general, they found no explicit guidelines for determining client priorities. Only a few sites offered an organized approach to monitoring the status of clients. The case manager role and its requirements appear to need clarification to achieve quality outcomes (Mor et al., 1988; Harder+Kibbe, 1994).

Ethical and Legal Issues

On the ethical side are the following issues: client self-determination, client advocacy versus loyalty to employing organization, and professional standards versus organizational standards. On the legal side are the following issues: fiduciary responsibility and rationing, confidentiality and informed consent, quality and outcome of service and discrimination. Resolution of these issues is often extremely difficult because definitions of legal and ethical issues are often ambiguous. The use of cost containment as a standard for making health care decisions is a complex undertaking that has raised interesting ethical and legal questions (Cornelius, 1994).

Ethical issues

Even when the patient's opinions or plans seem unreasonable or contrary to the agency or family treatment or disposition plans, the case manager must respect and protect the client's right to self-determination, unless that right is reversed by court order. Aroskar (1989) points out that in a broader sense, decisions made by and for an individual with HIV also have consequences for others in the community. While patient goals and values should always be considered in health care decisions and the person treated as an equal, the individual's decisions also may have consequences for others. Therefore, the patient also has obligations to others in the community.

The case manager must feel comfortable that he/she is doing no harm, is protecting the client against practices that may be harmful, and is promoting services that will benefit clients. The case manager must feel secure that cost containment and rationing decisions are not harmful to patients.

In the United States, there is a lack of consensus as to what constitutes a just social structure. (Aroskar, **1989**) As long as prejudice and discrimination against people with HIV affect political policy, research, and service availability, justice is not being realized. Justice is served when economic barriers are removed and HIV patients have equal access to required services (Bayer, 1990).

Traditionally, case managers have served as patient advocates but Kane (1988) raises the question whether a case manager can simultaneously serve as a patient advocate and as an agent of the managed care organization or a family member. This is an issue of mixed loyalties. Under a managed care program the independence of the case manager may be restricted.

Within managed care plans, to varying degrees, physicians and other health care practitioners come under the control and direction of corporate entities that are not only concerned with the provision of health care but with the price of stock and net earnings. While the fiscal strategies employed in managed care may be compatible with the achievement of quality of care at reduced cost, the managed care model produces conflicts and tensions because of the potential incompatibility of goals and the conflicting interests of the various participants. At times, measures to promote cost containment may produce conflicts between a staff member's professional and fiduciary responsibility to his or her client and that practitioner's legal obligations to the financial interests of the employing organization or self gain from financial incentives. (Rodwin, 1995) (McClinton, 95)

Legal issues

The protection of confidentiality has been an issue since AIDS first emerged. Many States have provided broad protection covering AIDS-related information but others have not. The stigma attached to the HIV diagnosis increases concerns about confidentiality, particularly when an outside organization is performing utilization review, conducting research, when there is insistence on group treatment over individual treatment, or when employee benefits are controlled by an outside Employee Assistance Program (EAP) (Mechanic, 1995). The effort to maintain confidentiality can produce a series of dilemmas between the case manager's responsibility to the client and his or her commitment to the rules of the employing organization. Confidentiality issues arise not only in relation to clinical practices but with respect to financial disclosures and dissemination of research data.

Confidentiality must be protected unless the client has provided written consent for disclosure or when reporting is mandated by law, such as in child or adult abuse or when required by court decision. In the Tarasoff case, the judge held that a health care professional, whose patient poses a threat to a third party, should take immediate steps to protect the potential victim even without gaining the patient's consent (Hermann, 1991). However, it is often difficult to decide just how imminent a threat is. Even in mandated cases, the client should be informed that a report is being made. Confidentiality is breached if family or agency contacts are established without client consent. Pressure to facilitate hospital discharge or treatment planning may tempt staff to bypass client confidentiality and self-determination.

Fiduciary responsibility stems from the legal requirement that an individual who has power over the affairs of another person must act in that person's behalf. It generally is accepted that health care staff should act as fiduciaries for their patients. There are two types of fiduciary conflicts: one relates to financial or personal interests and the second stems from divided loyalties resulting from competing obligations. Incentives to ration service as a means of reducing cost, in certain instances, may be construed as not in the patient's interest and can produce conflicts of interest that could compromise the welfare of patients (Rodwin, 1995). For example, a case manager could face legal repercussions if a discharge plan is compromised for cost-reduction purposes. Without the establishment of clear criteria governing what is a safe discharge the case manager may not be able to avoid the possibility of being negligent (Schreiber, n.d.). Mariner (1994) concludes that in the absence of an agreed-upon definition of medical necessity, a number of services will not be guaranteed unless covered by Federal legislation or regulation. He argues that without these guarantees there will continue to be considerable ambiguity,

and insurers will continue to be in a position to determine what is medically necessary for their subscribers. Under the current state of affairs some patients are appealing to the courts to rule on medical necessity.

The 1990 Americans with Disabilities Act provides a degree of protection against discrimination. While case management can offer some degree of protection against discriminatory practices by itself, it cannot eliminate prejudice and discrimination in the community. Case managers, however, can work as advocates jointly with other staff within their parent organizations and in the community to safeguard against discrimination.

In the past, informed consent focused primarily on the patient's right to be informed of the potential consequences of specific procedures and treatments. Under managed care, informed consent also is concerned with the extent to which prospective enrollees are informed of service restrictions or rationing before enrolling in a particular health care organization (Hall, 1993, 1994; Applebaum, 1993, 1994; Mechanic, et al., 1994). An ongoing argument centers on how much information is required for an informed decision. The courts are unclear whether managed care limitations on services need to be disclosed (Hall, 1993, 1994). Hall concludes that some rationing decisions need not be disclosed in circumstances where subscribers knowingly elect a payment program that allows for decisions based on cost containment.

On the other hand, Applebaum (1993) argues that lack of disclosure by the physician at the time of an economic rationing decision undermines any possibility of a meaningful patient role in treatment decisions. Mechanic (1994) objects to managed care organizations that market without disclosure of "constructive rationing" prior to the consumer's decision to enroll. He is concerned that many patients do not understand managed care or the nature of the implicit agreement that defines their relationship to the health care organization. The issue is whether informed consent also applies to the provision of case management services. Do clients have the right to decide to participate in case management? How is this service described to patients (Kane, 1988)?

Summary

Undertaking case management research is a complex task because of the number of service and organizational models that exist for the different patient populations and the continued introduction of new plans. The study of case management has been further complicated by the introduction of managed care.

It has been extremely difficult to determine how effective these various approaches have been in terms of fostering cost saving and quality outcomes. Improvement in access seems to be the most consistent findings. Thus far, studies of cost savings and quality have been inconclusive or questionable.

The absence of strong scientific data reduces the political potential of the case manager. It will take additional time before we will know how helpful new approaches will be in promoting public policy and legislation favorable to people with HIV.

Case management is not a panacea for eliminating all of the problems confronting persons with HIV disease or the organizational problems facing agencies serving those individuals. The practice of case management is extremely dependent on political priorities for the acquisition of required funding and constructive policy reform. It cannot maximize its function when required services are not available in the community, and it cannot by itself erase the prejudice and discrimination that plague many people with HIV disease. There is general agreement that case management is capable of increasing access to services, providing coordination and continuity . These accomplishments alone may be sufficient justification for supporting case management (Harder +Kibbe, **1994**; Levy et. al., **1992**).

References

Alemi, F., Stephens, R.C., Butts. Case management: A telecommunications practice model. Research Monograph Series, Progress and Issues in Case Management # 127, Ed. S.A. Sager, National Institute on Drug Abuse, 1992: 261-273.

Americans with Disabilities Act of 1990, P.L. 101-336, 104 Stat. 327.

Applebaum, P.S. Must we forgo informed consent to control health care costs? A response to Mark A. Hall. *The Milbank Quarterly*, **71**, 1993:559-576

Aroskar, M.A. Research in community-based care of persons with AIDS: An ethical framework, community-based care of persons with AIDS: Developing a research agenda. *AHCPR Conference Proceedings*, U.S. Dept. of Health and Human Services, PHS, Agency for Health Care Policy and Research, 1989:127-131.

Baker, R.J., McCormack, J.J. Continuity of case management: New concepts in hospital admission/discharge planning. Staff Paper, New York State Planning Commission, July 1984.

Bayer, R. Caring for HIV-infected individuals in the community: Ethical issues in the epidemic's next phase, community-based care of persons with AIDS: Developing a research agenda. AHCPR Conference Proceedings, U.S. Dept. of Health and Human Services, PHS, Agency for Health Care Policy and Research, 1989: 117-126.

Beresford, E. Uncertainty and the shaping of medical decisions. Hastings Center Report, July-August, 1991: 6-11.

Brookmeyer, R., Frank, R.G. Cost sharing, managed care and inpatient psychiatric utilization in private insurance. Johns Hopkins University (unpublished), 1993.

Brown, R.S., Bergeron, J.W., Clement, D.G., Hill, J.W., Retchin, S.M. Does managed care work for medicare? An evaluation of the medicare risk program for HMOs. Mathematica Policy Research Inc., Princeton, N.J., 1993.

Cheh, V., Keyes, M. Profile of the AIDS-related services in four States. Mathematica Policy Research Inc, Princeton, N.J., 1994.

Colone, M.A. Case management and managed care: balancing quality and cost control. *Social Work Administration*, Vol 19, No 3:7-10, Summer 1993.

Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1995.

Cornelius, D.S. Managed care and social work, constructing a context and a response. *Social Work In Health Care* Vol 20, No 1: 47-63, Nov. 1, 1994.

Dennis, M.L., Karuntzos, G.T., Rachal, J.V. Accessing additional community resources through case management to meet the needs of methadon clients. *Research Monograph Series*, Progress and Issues in Case Management No. 127, Ed. S.A. Sager, National Institute on Drug Abuse, 1992: 54-77.

Desimone, B.S. The case for case management. *Continuing Care*, July 1988:22-23.

Falck, R.S., Siegal, H.A., Carlson, R.G. Case management to enhance AIDS risk reduction for injection drug users and crack cocaine users: Practical and philosophical considerations. *Research Monograph Series No. 127*, Ed. S.A. Sager, National Institute on Drug Abuse, 1992: 167-180.

Fox, D.M. The consequences of consensus: American health care policy in the twentieth century. *The Milbank Quarterly* Vol. 64., No. 1: 76-99, 1986.

General Accounting Office. Medicaid: States turn to managed care to improve access and control costs. GAO/HRD-93-46, Government. Printing Office, Washington, D.C., 1993.

Hall, M.A. Informed consent to rationing decisions. *The Milbank Quarterly*, No 71, 645-68, 1993.

Hall, M.A. Disclosing rationing decisions: A reply to Paul S. Applebaum. *The Milbank Quarterly* Vol. 73, No. 2: 211-215, 1994.

Harder + Kibbe Research. Review of case management and HIV. December 1991:1-14.

Harder+Kibbe Research. Coordination of care, a new approach to services for persons with HIV. San Francisco, June 1994: 1-27

Henderson, M.G., Collard. Measuring quality in medical case management programs. *QRB*, February 1988: 33-39.

Hermann, D. *AIDS and the Law*. ed. Reamer, F.G. AIDS and Ethics, N.Y., Columbia University Press, 1991: 277-310.

Hurley, R.E., Freund, D.A., Paul, J.E. Managed care in medicaid: Lessons for policy and program design. Ann Arbor, MI. Health Administration Press, 1993.

Kane, R., Penrod, J., Davidson, G., Moscovice, I. What cost case management in long-term care. *Social Service Review* 65(2): 261-303, 1991.

Kane, R.A. Case management in health care settings. in *Case Management in Human Service Practice*, ed. Weil and Karls, Jossey-Bass, San Francisco, 1985.

Kane, R.A. Case management: Ethical pitfalls on the road to high-quality managed care. *QRB*, May 1988: 161-66

Klein, A., Thornton, C. Profile on the **medicaid** home and community-based care waivers for people with AIDS or HIV infection. **Mathematica** Policy and Research, Princeton, N.J., August 1994.

Knickman, J.R., Benjamin, A.E., Dunham, N.C. Comparing the cost effectiveness of alternative models for organizing services for persons with AIDS. National Center for Health Services Research and Health Care Technology Assessment, U.S. Dept. of Health and Human Services, May 1988:28-34.

Levi, J. Protection of personal rights, public policy in AIDS research and reporting. ***AIDS and Patient Management: Legal, Ethical and Social Issues***, 1986: 60-63.

Levy, J.A., Gallmeier, C.P., Weddington, W.W., Wiebel, W. W. Delivering case management using a community-based service model of drug intervention. Research Monograph Series No. 127, Ed. S.A. Sager, National Institute on Drug Abuse, 1992: 145-166.

Lidz, V., Bux, D.A., Platt, J.J., Iguchi, M.Y. Transitional case management: A service model for AIDS outreach projects. Research Monograph Series No. 127, Ed. S.A. Sager, National Institute on Drug Abuse, 1992: 112-144.

Lutz, S. For-profits had record earnings in 3rd quarter. ***Modern Health Care***, November 28, 1994: 5.

Mariner, W.K. Health law and ethics, patients' rights after health care reform: who decides what is medically necessary? ***American Journal of Public Health***, Vol 184, No 9: 1515-1520. Sept. 1994.

McCarthy, E.P., Feldman, Z.T., Lewis, B.F. Development and implementation of an organizational case management model for substance users, progress and issues in case management. Research Monograph Series No. 127, Ed. Sager, S.A., National Institute on Drug Abuse, 1992: 331-349.

McClinton, D.H. Balancing the issue of ethics in case management. ***Continuing Care***, June 1995:13-16.

McMillan, D., Cheney, R. Aftercare for formerly homeless, recovering women: issues for case management. Progress and Issues in Case Management Research, Monograph Series 127, Ed. Sager, S.A., National

Institute on Drug Abuse, 1992: 274-266.

Mechanic, D. Trust and informed consent to rationing. The *Milbank Quarterly*, Vol.72, No 2: 217-223, 1994.

Mechanic, D. ,Schlesinger, McAlpine, D.D. Management of mental health and substance abuse services: state of the art and early results. *The Milbank Quarterly*, Vol.73, No.1:19-52, 1995.

Miller, R.H., Luft, H.S. Managed care plan performance since 1980 - a literature analysis. *Journal of the American Medical Association*, May 18, Vol 271, No 19: 1512-1519, 1994.

Millman, Al, The impact of physician financial incentives on high-risk populations in managed care. *Journal of Acquired Immune Deficiency Syndrome and Human Retroviruses*, 8: 525-530, Suppl.1, 1995.

Mohr, P.E. Patterns of health care use among HIV-infected adults: preliminary results. ACSUS Report, No.3. U.S. Dept. of Health and Human Services, Agency for Health Care Policy and Research, Sept. 1994

Mor, V., Piette, J., Fleishman, J. Grant Watch, I. Essay- community-based case management for persons with AIDS. *Health Affairs*, Winter 1989: 139-153.

Nacman, M. Case management training manual, New York State Dept. Of Health, AIDS Institute, 1990.

Omnibus Budget Reconciliation Act (OBRA):1981.

Rapp, C.A., Chamberlain, R. Case management services for the chronically mentally ill. *Social Work*, 30: 417-422, 1985.

Richmond, J.B. The health care mess, a bit of history. *Journal of the American Medical Association*, Vol. 273, No. 1: 69-71, January 4, 1995.

Ridgely, M.S., Willenburg, M.L.. Application of case management to drug abuse treatment: overview of models and research issues, progress and issues in case management. Research, Monograph Series No. 127, Ed. S.A. Sager, National Institute on Drug Abuse, 1992:12-33.

Rodwin, M.A. Conflicts in managed care. *The New England Journal of Medicine*, March 2, 1995: 604-607

Schlenger, W.E., Kroutil, L.A., Roland, E.J. Case management as a mechanism for linking drug abuse treatment and primary care : Preliminary evidence from the ADAMHA/HRSA linkage demonstration. Research, Monograph Series 127, Ed. S.A. Sager, National Institute on Drug Abuse, 1992: 289-315.

Spitz, B. A national survey of **medicaid** case management programs. *Health Affairs* 6: 61-70, Spring 1987.

Tannenbaum, S.J. Knowing and acting in medical practice: The epistemological politics of outcome research. *Journal of Public Health, Policy and Law*, Vol. 19, No.1: 27-44, Spring 1994.

Tarasoff v. Regents of the University of California, 17 Cal. 3rd 425, 551 P.2d 334, 131 California Reporter, 14 **aff'g** in part 529 P. 2d 553, 118 Cal. Rpt.129, 1976.

The New York Times, Vol. CXLIV, No 50,.117, Sunday, July 9, 1995

Times Union, from the *New York Times*, Rochester , N.Y., July 5, 1995:1.

Toth, C.J. AIDS case management: what health insurance companies are doing. Health Insurance Association of America, Washington, D.C., 1988.

Vladek, B.C. AIDS policy: a long term view. Chapter 24, AIDS, *Public Policy Dimensions* 1987: 239-242.

Weil, M. Key components in providing efficient and effective services, in case Management in human service practice. ed. M. Weil and J.M. Karls (San Francisco) Jossey-Boss, 1985

Witek, J.E., Hostage, J.L. Medicaid managed care. *Journal of Ambulatory Care*, Vol.17, No.1: 61-69, 1994.

Yarmolinsky A. Sounding board, "Supporting the patient". *The New England Journal of Medicine*, March 2, 1995: 602-603.

A Review of Systematic Data Analysis Toward the Effectiveness of HIV Case Management

*Jaime L. Amsel, Ph.D., J. Raúl Magaña, Ph.D., and Cécile P. Tran, B.Sc.**

This paper describes a rationale for using a model of case management for delivering services to people with HIV disease. It begins with a review of published HIV case management models. The need for evaluation research to inform the development of new case management programs is highlighted and the optimal characteristics of measures used to assess program effectiveness are outlined. Next, two concepts are presented for approaching the evaluation and development of case management models for people with HIV disease. These concepts have the potential to greatly enhance the quality of services provided to people with HIV disease and could further the scientific understanding of HIV treatment. The first concept is a non-traditional methodology called systematic data collection and analyses. The approach is quantitative but with a qualitative base and “flavor.” The authors illustrate how to apply this methodology to the development and evaluation of HIV case management models. The second concept proposes the inclusion of empowerment (“conscientization”) to the development and evaluation of new HIV case management models.

*The authors are with the University of California, Irvine, Health Policy and Research.

Introduction

AIDS had claimed more than 220,000 lives in the U.S. by the end of 1994, with an additional 1.1 million Americans infected with HIV (Japsen, 1994a). New treatments for HIV disease have significantly increased life-expectancy and have shifted the status of the illness from an acute short-term terminal disorder to a progressive chronic one (Twyman and Libbus, 1994) with no cure in sight (Japsen, 1994a). In 1987, the average dollar loss of treating an AIDS inpatient was \$5,818 per patient in public hospitals and \$2,381 in private hospitals (Larkin, Koska, Hudson, and Eybanks, 1990). This has meant that the cost of treating a person with the HIV virus from diagnosis until death has increased rapidly. More recently these costs have been estimated at \$150,000 to \$160,000 by the Physicians Association for AIDS Care (Japsen, 1994a), with some costs as high as \$200,000 (Japsen, 1994b). As the cost of treating AIDS patients has increased, hospitals have begun looking at ways to contain costs, prompting a shift from inpatient care to outpatient and home care treatment (Holzemer, 1992).

Case Management

The case management model has been promoted as a way to contain costs for medical treatment (Larkin et al., 1990). It involves the management of services provided to individual patients in an effort to deliver more cost-effective care (Aseltyne, Cloutier, and Smith, 1995). Historically, case management systems were implemented to serve chronically ill populations: the mentally ill, the developmentally disabled, the frail elderly, and the recently hospitalized cancer patient (Piette, Fleishman, Mor, and Dill, 1990). More recently, case management has been applied to people with HIV disease (Twyman et al., 1994).

A definition

The Robert Wood Johnson Foundation (RWJF) AIDS Health Services Program defined the goals of case management as first, to improve the quality of patient care, second, to enhance the quality of life, and lastly, to contain costs (Larkin et al., 1990).

Case management was also viewed as a strategy that increased clients' access to services, decreased their unmet psychological and health needs, and reduced the costs of hospital stays (Sowell and Meadows, 1994). Gunter and

Joyce (1993) contended that effective case management, provided by a case manager and home nursing provider at the onset of the illness, can ensure that clients receive cost-effective, quality care. In the case example Gunter and Joyce (1993) discussed, the client “died 15 months after the initial diagnosis; the total insurance bill was \$25,000 - the approximate cost of 25 days in a hospital.” Schull et al. (1992) studied the effects of case management for all patients with HIV infection, ARC, or AIDS admitted to Parkland Memorial Hospital, a public hospital in Dallas, Texas, from January 1, 1986 through December 31, 1990. The study found that the average length of stay in the hospital decreased from 11.66 days in 1986 to 8.2 days in 1990 although the number of AIDS patients increased from 212 in 1986 to 913 in 1990.

Another definition

The Case Management Task Force in Orange County, California (established in 1994), viewed case management as a collaborative process that assessed, planned, implemented, coordinated, monitored, and evaluated the options and services required to meet an individual's health needs, using communication and available resources to promote quality and cost-effective outcomes.

Services were best offered when there was direct communication between case manager, client, and appropriate service personnel. Holzemer (1992) also believed that case management should place the responsibility for health with the patient, family, and community, and that case managers assist with the coordination of appropriate and affordable health services.

The proliferation of case management for people with HIV disease was fostered by a variety of public and private funding (Piette et al., 1990). The New York State AIDS Designated Centers, a hospital-based system of AIDS care, must provide case management to receive enhanced reimbursement from the State's Medicaid program (Piette et al., 1990). The Robert Wood Johnson Foundation (RWJF) funded the development of case management systems in Atlanta, Dallas, Ft. Lauderdale, Jersey City, Miami, Nassau/Suffolk, New Orleans, Newark, Seattle, and West Palm Beach. Both

hospital- and community-based models were implemented to foster flexibility in the design of systems that would best suit a parent agency's operating procedures and best meet the needs of the local AIDS population (Piette, Fleishman, Mor, and Thompson, 1992). In addition, the Ryan White CARE Act of 1990 recognized that hospital-based outpatient care is a key component of effective HIV care and targeted funding for outpatient and community-based services (Japsen, 1994a). Case management will remain a central component of the HIV service system in the years to come (Piette et al., 1990).

What is the role of the case manager?

A case manager's job is to guide a client through the complex maze of the health care system and to coordinate and monitor the provision and quality of inpatient and outpatient care, home care, visiting nurses, mental health care, food, housing, transportation, and personal care services (Larkin et al., 1990). Piette et al. (1992), in their study of the RWJF case management programs, found that all case managers surveyed agreed that the core of their job is to link their clients with financial, social, and medical services. Piette, Thompson, Fleishman, and Mor (1993) also suggested that HIV case managers with a bachelor's degree in social work (BSW) have the combination of skills needed to serve their clients: these professionals are trained in the linkage of concrete services and in dealing with psychological issues. According to Holzemer (1992), case managers could be clinical psychologists, social workers, nurses, or physicians, depending on the level and type of services required.

Orange County's levels of case management

The Case Management Task Force (1994) in Orange County, California, identified three major levels of case management: primary, secondary, and tertiary. The primary level case manager is typically an HIV counselor and a health educator with a basic understanding of risk assessment, community resources, public and private benefits programs, medical aspects of HIV infection, and cultural sensitivity. The secondary level requires a social services case manager skilled in counseling and education. The tertiary level case manager must be a registered nurse or a licensed social worker/counselor with a graduate degree and medical training.

Other skill sets that have been identified as necessary for quality case management are those possessed by the public health nurse (Larkin et al., 1990) and the clinical nurse specialist with at least a baccalaureate degree (Schull, Tosch, and Wood, 1992) and the educational background and clinical expertise to fulfill the roles of clinician, educator, collaborator, and researcher with an added management focus (Cronin and Maklebust, 1989).

Case manager roles differ greatly in hospital-based and community-based organizations (CBOs). The latter initially provided the volunteer supports that characterized HIV care in the early years (Piette et al., 1990). In recent years, CBOs have become the new providers of health care service; they are required to take on a more professional role and are expected to compete for funding at the Federal, State, and local levels (Grier and Sowell, 1993). This trend suggests the need to develop standards of care and an objective evaluation process in case management (Grier et al., 1993). In a comparative study conducted by Piette et al. (1990), 68 percent of CBO case managers reported that they had neither a degree in social work or nursing, whereas 64 percent of hospital-based case managers had a degree in social work and 15.2 percent had a nursing degree. Overall, CBO case managers reported having greater difficulty than hospital case managers in obtaining several key services: residential drug treatment, outpatient drug treatment, entitlements, home health care, and homemaker services. Piette et al. (1990) also found that hospital case managers served a large proportion of intravenous drug users (IVDU) and clients in need of long-term care, housing, transportation, and psychological counseling while their CBO counterparts served a predominantly gay/bisexual clientele needing emotional support and legal advice. Due to this divergence in the roles and abilities of both hospital and CBO case managers, Piette et al. (1990) suggested that hospitals and CBOs alternate their primary responsibility for a given case depending upon the client's medical status: CBO case managers would maintain contact with functionally stable clients while hospital case managers would be responsible for clients who were more economically disadvantaged.

Current trends indicate changes in the demographic distribution of those infected with HIV. In California between 1990 and 1991, the percentages of AIDS diagnoses among the gay/bisexual cases dropped from 82 percent to 74 percent whereas the rates for other groups increased. Rates increased among

IVDU_s (from 7 to 9 percent) and heterosexuals (from 1.7 to 2.4 percent), Hispanics (from **13** to **17** percent), and African-Americans (from 12 to **14** percent) (Holzemer, **1992**). By **1992**, the Centers for Disease Control (CDC) reported over 175,000 confirmed AIDS diagnoses: 59 percent were homosexual/bisexual; **16** percent were Hispanic; 28 percent were **African-American**; and an estimated 80,000 pregnant women were infected (Holzemer, 1992). Given the increased prevalence of the disease and the changing demographic characteristics of people with HIV, it is very likely that most health care workers will soon be involved in the care of someone who is seropositive (Holzemer, **1992**). A flexible case management system is needed that responds to the needs of culturally, socially, and geographically diverse groups of persons with HIV at each stage of the illness.

Case management models

AIDS Project Los Angeles

One of the earlier models of case management was implemented at AIDS Project Los Angeles (APLA) in 1986 to meet the needs of clients who suffered from social discrimination, isolation, and benefits rejection and who had become very dependent on the organization (Sonsel, Paradise, and Stroup, 1988). APLA's case management program embodied the elements of advocacy, continuity of care, and cost-containment models. Its goals have been to increase client access to services; coordinate inter- and intra-agency services; maintain client's highest level of physical, psychological, social, and spiritual functioning; monitor the quality of services provided; and reduce the duplication of services within the community. Cases were assigned on the basis of a client's geographic location or specific needs (such as the need for a bilingual case manager). The case manager-to-client ratio of **1:125 was** buffered by the coordination of a case management team comprised of a case manager (social worker), an insurance counselor, a transportation coordinator, and volunteers, as well as management and administrative personnel. The program accommodated the complex social, psychological, and health care needs of its clients in spite of difficulty in client tracking, fund accounting, comprehensive use of referral resources, and coordination of services due to increasing case manager-client ratios.

The Group Health Cooperative of Puget Sound

By **1990**, the Group Health Cooperative of Puget Sound (GHC) was the third largest provider of services to HIV-infected individuals in the State of

Washington. GHC consisted of two hospitals, 30 clinics, and 600 medical staff serving 400,000 members (Philbin and Altman, 1990). The AIDS Care Coordination Program, a home-based HIV social case management service initiated in 1987, evolved from the need to provide quality home care to people living with AIDS. The service provided anticipatory planning, advocacy, counseling, and communication within GHC and with other community service provider organizations. Approximately 110 clients have used the home-based social case management services. The case manager, a masters-prepared social worker (MSW), collaborated with the primary care medical team of physicians and nurses. A significant advantage of working within a health maintenance organization (HMO) is the opportunity to maximize the continuity of care between settings and levels of care. A screening/assessment tool was used to facilitate exchange of information about the client at the time of hospitalization and discharge. The case management service goal was to assist patients in remaining at home longer. The intensity of intervention was determined by the patient's needs and medical conditions: some were contacted by phone monthly while others were seen one or two times a week. The average length of stay in 1989 was 6 month; stays ranged from 3 months to 2 years. In 1989, a total of 25 AIDS patients died within GHC. Of the 17 who received home-based case management, 3 (18 percent) died in the hospital, 2 (12 percent) died in adult family home, and 12 (70 percent) died at home. The eight patients who did not receive home-based case management services died in the hospital.

The Contra Costa County AIDS Case Management Program

The Contra Costa Health Department in Martinez, California, considered AIDS a chronic disease with a wide spectrum of needs (Kerson, 1991). Beginning in 1991, the Contra Costa County AIDS Case Management Program was a 3 year pilot project funded by the State to provide support to a diverse population with HIV: pediatric AIDS patients, men and women infected with HIV, and various ethnic group members with HIV. The case management team was comprised of a public health nurse (home care services), a social worker (counseling, living arrangements, food, public welfare), a legal advocate, a financial and insurance counselor, and volunteers. The case manager was a health care professional who served as patient advocate and coordinator of services from intake to evaluation of services.

The Robert Wood Johnson Foundation AIDS Health Services Program

The RWJF undertook a study of nine AIDS case management programs it had funded and concluded that effective case management is more an art than a science (Piette, Fleishman, Mor, and Thompson, 1992). Most case managers

interviewed agreed on the following components needed for successful case management:

- . a comprehensive assessment to determine medical, psychological, financial needs;
- a care plan that maps out the process and links resources;
- . linkage of clients with financial, social, and medical services as needed;
- . ongoing monitoring of changes in the client's condition; and
- . client advocacy for access to services and benefits.

However, without a systemic approach to case management, the case managers found themselves responding to crises rather than monitoring care plans, which were non-existent in most cases. To ensure that the services were delivered effectively, the authors recommended that protocols and guidelines serve as standards for documentation procedures. This was to ensure that the services were delivered effectively.

Pilot Care and Waiver Projects, California Department of Health Services
Pilot Care Projects, a State-funded case management program, was implemented in 1986 by the California Department of Health Services, Office of AIDS (DHS/OA) to provide statewide home-and community-based care to persons with AIDS (PWA) in their latter stages of HIV illness. The Waiver Project, a Federal Medicaid waiver case management program in California, was begun in 1989. The core case management team was comprised of a nurse case manager, a social worker, a physician, the client, the client's partner and family members, who worked together to develop a service plan. This interdisciplinary case management provided the coordination and linkage of community services and a service delivery model using nurse case management. In these programs, the DHS/OA developed protocols to be implemented in all sites by 1990. These protocols contained the following elements:

- complete initial nursing/health assessment;
- . initiate and guide service planning;
- . implement and monitor service delivery;
- . evaluate and reassess client;
- . case management team conference;

REVIEW OF SYSTEMATIC DATA ANALYSIS

- . develop quality assurance program; and
- . collect and submit data on service utilization.

The results of a study of these programs validated the interdisciplinary case management model in a community-based organization serving the HIV infected population (Wright, Henry, Holzemer, and Falknor, **1993**).

Case Management Task Force of Orange County, California

The Case Management Task Force of Orange County, California, developed a continuum approach to case management. This consisted of a linear progression of levels of care that matched the stages of the illness: primary case management with counseling, assessment, and training at the onset of the disease; secondary case management in the asymptomatic stages where social services were sufficient; and tertiary case management in the more advanced stages where medical services became crucial (Case Management Task Force, **1994**).

The Missouri Medicaid AIDS Waiver Program

Missouri had one of the higher AIDS rates in the central portion of the United States. The Missouri Department of Health (MDOH) implemented the first statewide case management program for AIDS and HIV-positive clients in 1988 (Twyman and Libbus, 1994). The role of the case manager was to locate, expedite, coordinate, monitor, and assure the quality of the services. In **1989**, the Missouri Medicaid AIDS Waiver program was initiated with a specific aim at cost containment by reducing the overall days of inpatient hospitalization and providing home care services with attendant care and medical supplies for case managed HIV clients. Twyman et al. (**1994**) conducted a retrospective investigation that focused on the 6 months preceding death, using the death certificates of 100 randomized cases and 99 controls. The cases were deceased clients who received at least 6 months of case management services from the statewide program. The controls, due to their insufficient number, were a convenience sample of individuals diagnosed with AIDS and not enrolled in MDOH case management services. Both cases and controls were required to have had medical assistance from Missouri Medicaid for a minimum of 6 months preceding death. The results did not support the premise that MDOH case management services reduced the number of inpatient days in AIDS clients.

AID Atlanta, Inc.

AID Atlanta, Inc. developed an integrated case management model that has been operating since 1986 and was funded as part of the RWJF AIDS Demonstration Project (Sowell and Meadows, 1994). The interdisciplinary model used the expertise of social workers, nurses, pastoral counselors, and therapists to develop client-centered care plans. There were four phases: 1) brief contact form for follow-up; 2) medical intake for assessment of needs; 3) low-need client services for the implementation of case planning before crisis; and 4) high-need client services for the handling of emotional, physical, and financial crises. The model's key component was client involvement and responsibility during the process of assessment, proactive planning, implementation, and evaluation/reassessment. An ongoing interaction between client and case manager was encouraged. The development of the standards and procedures focused on the process and outcome determinants: the actual process, the client's role, the case manager's role, high- or low-need clients, and outcome criteria. Ongoing actions to assist clients also were documented. This model develops a full partnership between clients, case managers, and clinic staff.

The San Francisco Model

The San Francisco model of case management was established as a template of services ranging from residential to acute care designed to meet the needs of people with HIV disease, following closely the principles of the Ryan White CARE Act of 1990 (Morrison, 1993). The services included an inpatient unit, an outpatient unit, high-technology health care, community-based counseling for both clients and their families, homemaking, skilled nursing facilities, transportation, education and prevention programs for people at risk, and financial and legal advice. Table 1-1 summarizes the key features of these nine models of HIV case management.

Table 1-1**Characteristics of Models of HIV Case Management¹**

Model	Location	Year begun	Target population	Funding	Focus	Key elements
APLA	Los Angeles, California	1986	Gay/bisexual men, IDUs & sex partners, and pediatric	Government, private, organized philanthropy	Social, psychological, health care	Case manager-client ratio of 1:125 (targeted to be reduced to 1:75); 22% minority clients; mean age 32 years
GHC	Puget Sound, Washington	1987	Class IV diagnosis	HMO	Social, psychological, home health care	76% of home care clients died at home
Contra Costa County	Martinez, California	1991	All HIV+ people & their partners with HIV, pediatric	State	Social, psychological, health care	Strength in the linkage of service and care plan documentation
RWJF AIDS Health Services	Multiple	1992	HIV+	RWJ Foundation	Social, psychological, health care	Case managers in crisis intervention recommend care planning
Pilot Care & Waiver Projects	California	1986	People with AIDS	State and Federal	Social, psychological, health care	Interdisciplinary, home & community-based case management
Case Management Task Force	Orange County, California	1994	HIV+ county residents	State	Social, psychological, health care	Defining stages of case management
Missouri AIDS Waiver	Missouri	1988	AIDS & HIV+	State	Social, psychological, health care	Care coordination

¹ No evaluation data available for any of these models.

Table 1-1
Characteristics of Models of HIV Case Management ¹

Model	Location	Year begun	Target population	Funding	Focus	Key elements
AID Atlanta	Georgia	1986	HIV+	RWJ Foundation	Social, psychological, health care	Client involvement and responsibility in case management
San Francisco Model	San Francisco	1993	HIV+	RWJ Foundation	Social, psychological, health care	Template of services, emphasis on outpatient

Criteria for Selecting Data Gathering and Analyses Methodologies

Within the domain of program evaluation research, there has been very little, if any, research that practitioners can draw on to develop their own case management models. In the area of treatment models for people with HIV, researchers and practitioners alike have stated that "...little research has been conducted on models of care for HIV-infected persons, and the need for more data continues to be extensive." (Morrison, **1993**; Priority Expert Panel on HIV Infection, 1990). The development of the existing models followed some data collection and analysis methodology that might be considered more intuitive than scientific, as illustrated in the results of the study of the RWJF demonstration grants. Piette et al. (**1992**) commented that the case management process in the various sites was more an art than a science. The present authors do not suggest that this process produced deficient models. On the contrary, some models have worked well for people with HIV. Yet in order to accumulate good data on how these models work and how they can be adapted to specific populations, comparable data gathered in a scientific manner is necessary.

The choice of criteria for data collection in the context of HIV case management must consider a range of factors that affect the relevance and applicability of the results. The measures should be:

- **As unobtrusive as possible:** Aaronson (1991) suggests that "...research designs and data collection procedures should be selected in a way that

minimizes patient, medical staff, and institutional burden.” This viewpoint is totally understandable within the context of shrinking resources and with increasing needs in HIV case management. Additionally, unobtrusive measures often are less susceptible to bias.

- ***Multidimensional and able to tap each individual’s subjective perception of his or her needs:*** With the transformation of the HIV disease toward a chronic disorder, ensuring the best possible quality of life for the patient is an integral part of the treatment. Quality of life is a subjective and multidimensional construct. Data collection techniques should be designed to be as sensitive to these complexities as possible (Butters et al., **1992**).
- ***Systematic and open to analytic comparison across models and theories of care:*** Due to the variability and relative newness of the disease and infection prevalence, there is no substitute for the systematic development of timely local knowledge as the basis for planning (McCann et al., 1993). Since there is more than one good model of care, all models should be flexible enough to deal with needs on an individual basis (Layzell and McCarthy, **1992**).²
- ***Applicable in different and localized geographical, ethnic, cultural, sexual orientation, and gender environments:*** Morrison (1993) pointed to the need to identify the “secondary world view” that reflects the folk beliefs of a particular culture. In addition, Piette (1993) reported that 40 percent of AIDS patients reported unmet needs and that women, people of color, and drug addicts reported higher levels of unmet needs.

Systematic Data Collection and Analysis Methods

We suggest the systematic data collection methodology as the best approach to use when attempting to develop an HIV case management model (Weller and Romney, **1988**). The data collected through this method addresses our own criteria (cited above) but they also can be analyzed by a group of quantitative methods known as hierarchical clustering (Johnson, **1967**). This

² The authors note that local knowledge needs to be the basis as well for the development of case management models; and that the analytic methodologies of the models should be flexible.

includes multidimensional scaling (Kruskal and Wish, 1988), correspondence analyses (Weller and Romney, 1990), quadratic assignment procedure (Hubert and Schultz, 1976), and consensus analyses (Romney, Bachtelder, and Weller, 1987). Multidimensional scaling and consensus analysis methodologies applied to case management model development are described below.

Multidimensional scaling

Multi-dimensional scaling is a multivariate technique that provides a visual as well as a quantitative representation of perceptions of items of informants within a conceptual domain. In the same way that factor analysis (a linear procedure) reduces a complex matrix of interrelationships to fewer factors, multidimensional scaling reduces the matrix to a limited number of dimensions. With this technique, the relationships among items are then depicted in spatial and graphical terms with each item represented as a point in space. Relationships between items are translated into distances, so that similar items are closer to each other and dissimilar ones are farther apart (Ruebush II et al., 1994).

Consensus analysis

Consensus analysis is a technique that allows measurement of the competence and knowledge of each informant or participant. It also allows researchers to reconstruct the correct answers “with about as much assurance as if we had the actual answers” (Weller and Romney, 1988). Consensus analysis is a kind of reliability analysis performed on people instead of variables (Weller and Romney, 1988, pp. 75). A consensus analysis will result in scores revealing the amount of agreement among participants within groups (e.g. how much do patients agree among themselves that the items chosen reflect their preference order of their needs), and between groups (e.g. how much agreement there is, if any, between the services patients need; between the case managers and the patients). The analysis also can provide a score on “cultural knowledge” that would allow scientists and case managers to identify who among their participants or clients has a better share of the relevant information regarding case management. Participants later could serve in focus group sessions to develop case management programs.

In addition, consensus analyses will produce a score to compare different groups by using Hubert and Schultz’s (1976) quadratic analysis procedure. The methodology permits group comparison to understand what and where the differences in perspectives exist between groups such as service providers, funding or monitoring agents, and service recipients or patients. The procedure also can compare different participant groups (e.g. between

substance abusers and non-substance abusers, between different ethnic groups, etc.). This understanding in turn can be a feedback for the development of case management programs designed for specific communities or populations.

Data systematically gathered can be entered into a statistical package such as **Anthropac** for analysis (Borgatti, **1992**). The program will produce matrices that can elicit a score for the amount of agreement among the participants regarding the specific items a case management model should include, for example, the prioritization of service needs among the people with HIV, or items that will result in evaluation of the effectiveness and efficiency of a specific case management model. The program will produce the consensus analyses scores for within-group agreement and between-group agreement or disagreement, and scores on “cultural knowledge” for each participant.

Finally, the program can present data graphically (multidimensional scaling, Kruskal and Wish, 1991, and hierarchical clustering, Johnson, 1967). This allows for data analyses and interpretation with the participation and input of individuals who do not necessarily possess statistical preparation (e.g. case managers and patients) but whose input is critical for a valid interpretation of results.

Advantages

Several major advantages are provided by the systematic data collection methodology and analysis methods over more traditional methods, especially for improvement of the understanding of health care issues in general and, particularly, across cultures (Weller et al., 1993).

The first major advantage is the small number of participants needed to achieve valid and reliable results: in most of the cases **20 to 30** participants per sample/group would suffice, and in some cases even 6 to 10 participants would suffice. Weller and Romney (1988) found that a sample size of 20 provides a confidence level of **0.95** or better when examining characteristics of cultural knowledge with participants with an average cultural competence of 0.6 or more.

An example of the validity and reliability of the methodology can be found in **Magaña** et al. (1981). The research team asked a sample of 25 participants, using different versions of the systematic data collection techniques, to reproduce the distances among **13** different landmarks in a campus well known to them. The resulting multidimensional maps matched, with a high degree of accuracy, the actual geographical distances between the items and

their location.

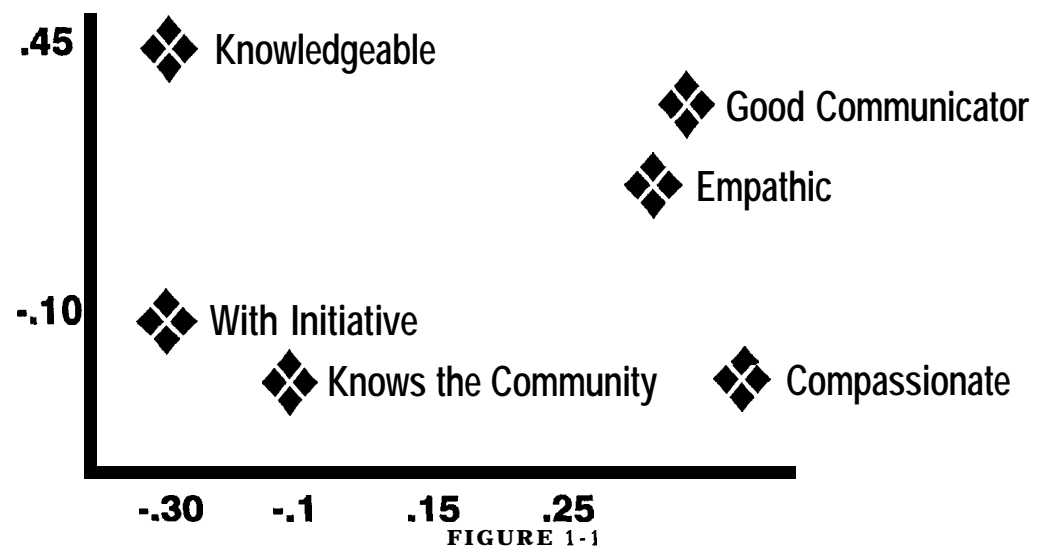
A second major advantage is the qualitative “flavor” of this methodology. Unlike surveys, these techniques for data collection allow for the collection of comparable data on non-standard items (data elicited by the participants themselves in their own terminology). The techniques are less susceptible to the “social desirability” bias. For example, when a traditional survey asks about the importance of 30 different patient needs on a 7 point scale, from *Not Important At All* to *Very Important* – patients could circle most items around *Very Important* (a scale range reduction effect) which in turn will require either sophisticated analyses techniques to differentiate between the items, or a large sample size to obtain significant differences among the mean scores assigned to the items, or a combination of both. On the other hand, in asking the patients to rank order all 30 items from *Most Important* to *Least Important*, the correspondence analyses, will overcome the problem of “None of these items is important” to them and provide an averaged rank order based upon what the individuals themselves decided.

The presence of non-metric algorithms in the methodology constitute the third major advantage because data is not required to be linear and/or normally distributed (Katz and Van Maanen, 1977). The clustering analysis technique develops “dimension- free” hierarchies; non-metric procedures typically yield fewer dimensions in their final solutions than the metric alternatives, providing greater simplicity (Katz and Van Maanen, 1977).

Finally, the results can be simply described, understood, and interpreted by individuals without sophisticated statistical formation. Case managers and their patients can then easily relate to the results of the data analysis.

The following is a graph of a possible result using the methodology described above. Suppose we were interested in determining the qualities of an efficient case manager in the eyes of his or her clients. After gathering the data, we would produce a multidimensional map below.

Figure 1 is a hypothetical “map” that would be generated by the methodology. When analyzed by clients and case managers, it would show that participants associate initiative with community knowledge and empathy with good communication skills. Perhaps the clients of this “survey” think that, in order to know their community, case managers need to take the initiative and, in order to come across as empathic, they should possess good communication skills. Another analysis would show that the term “knowledgeable” is in the vertical axes far away from the term “knows



the community.” Perhaps the clients perceive two separate realms of knowledge for a case manager – one regarding the specifics of their community and one regarding resource knowledge or medical knowledge. Comparing this hypothetical map to one elicited among case managers can show areas in which case managers are “blind” to the perceptual map of their clients and vice-versa, allowing for a rich training intervention in which case managers can learn to “read” the perceptual map of their clients.

Health Field **Applications** of the Data Gathering and Analysis Methods

We choose two recent examples from the existing literature that, although applied to malaria, easily could be adapted to HIV case management. The first example was a study conducted by Brieger (1994) who unveiled the usually “hidden” perceptive structure of the malaria disease symptomatology among the Yoruba in Nigeria. The author used the free listing and pile sorts data collection methodology that can be practiced with pre-literate individuals. Then he proceeded to multidimensional scaling to produce a perceptual “map” of the symptoms. The author found four clusters of symptoms of which three focused on the three different types of malaria as understood by the Yoruba and the fourth on symptoms either not associated with one type of malaria or presented by other sources of health care information. The results shed light upon how potential patients perceived the disease, and had clear implications for education and treatment plans to manage the disease. This same data collection and mapping analysis

technique can be used to tap the important fulfilled and unfulfilled needs of people with HIV enrolled in a case management program. Piette (1993) states that to effectively develop programs and allocate resources, information about the types of community services needed as well as the degree to which service needs remain unmet is critical. However, few studies have reported data addressing this issue. The proposed technique would address Piette's concern in an expedient manner.

The second example is a study conducted by Ruebush (1994) and his colleagues in the Pacific coast of Guatemala. The authors use the free listing method and rank ordering data collection methodology. (Again, this method can be easily used with pre-literate individuals.) Then they proceeded to multidimensional scaling to produce a perceptual "map" of the qualities most required of a malaria volunteer worker. The authors unveiled the qualities of an ideal volunteer malaria worker as perceived by potential patients and by government-paid malaria service staff.

Next the authors compared the "maps" produced by representatives of the community and representatives from governmental staff. The similarities and the differences between the expectations of these two groups were illustrative of the gaps that needed to be addressed when selecting and training malaria volunteer workers. This same methodology can be applied to different groups of people with HIV in a case management program. We can then quantitatively and qualitatively compare the needs of the target populations to the designs of community organizations or health care agencies staff. Moreover, the different rankings of various sub-groups (ethnicities, urban/rural, gender, sexual orientations) could be elicited and used in "fine tuning" the selection and training of managed care personnel. This fine tuning in turn could help to develop a case management program that addressed the concerns of women, people of color, and drug addicts who often report higher levels of unmet needs than do white males.

The **Empowerment Approach** to Model Development

HIV case management is an outpatient, community-based endeavor. For example, Marazzi et al. (1994) found that only 12 percent of patients were living on their own, while the rest were living and being cared for by family

(55 percent by parents) and friends. This implies that when it comes to HIV disease, family and friends are an important component in the quality of patient care. Unfortunately, this constituency often is ignored, much to the detriment of persons with HIV and the effectiveness of their service delivery. Another important constituency are volunteers giving care. There is concern about the heavy burden these volunteers carry (Morrison, 1993; Jenna, 1988; Andersen, 1988). An unusual degree of collaboration among diverse groups is necessary for case management programs to be effective (Morrison, 1993). Yet, there is a relatively high presence of unmet needs among people with HIV. Many have additional, sometimes more pressing problems than the HIV disease, such as drug addiction, unemployment, or under-employment (Marazzi et al., 1994).

One approach to meeting these unmet needs is coordination of a range or continuum of services (Priority Expert Panel on HIV Infection, 1990; President's Commission on the Human Immunodeficiency Virus Epidemic, 1988). This coordination would be handled best by an "empowered" client who could effectively and efficiently route his or her case management needs, since the recipients of the treatment would always know best about their needs. Gunter et al. (1993) illustrated a case of empowerment with the case study of a 40-year-old Illinois man diagnosed with AIDS in 1989. The provider offered a wide range of services from home-making to professional nursing. The focus was to empower the client: both the man and his family had a sense of control over decisions made about his care (Gunter et al., 1993). Empowered case managers, family members, volunteers, and community workers would best coordinate their efforts to meet the needs of an empowered client/patient.

Paulo Freire, a Brazilian philosopher and educator, has developed a very effective empowerment³ method which proved extremely effective in transforming unempowered and illiterate farm workers and factory workers into literate empowered individuals in a short period of time (Freire, 1970a; 1970b; 1971). Freire's postulates have been effectively applied to other areas of health, including alcohol and drug abuse (Wallerstein and Bernstein, 1988).

³"Conscientization" would be a closer translation.

Using Freire's ideas for the improvement of the status of people with HIV is not new (Magaña et al., 1992; Carpio et al., 1992; Amaro, 1995). Those ideas have been suggested mainly as a primary prevention method, yet these same ideas can be very powerful if applied to case management systems. This is especially important in lieu of the high number of unmet needs reported by people with HIV and the highly political nature of the disease. With shrinking resources for health care in general and increased numbers of individuals in need, case management requires drastic measures in which the person with HIV disease, the case manager, and the community are mobilized to provide services more efficiently.

Summary

Although art seems to prevail where science is lacking in the preceding case management models, there is a discernible common thread that weaves through them. They provide valuable services designed to address a variety of client needs. To date, there have been few efforts, if any, to systematically evaluate the effectiveness of those services. The need is pressing for evaluation research to develop HIV case management. Funding agencies need to increasingly demand evaluation of the effectiveness of the services they fund despite the difficulties of evaluation. Experimental designs are neither feasible nor ethically desirable. Therefore, the utilization of qualitative approaches employing formal methods needs to be recommended.

References

- Aaronson, N. Methodological issues in assessing quality of life in cancer patients. *Cancer*, 67, 844-850, 1991.
- Amaro, H. Love, sex, and power: Considering women's realities in HIV prevention. *American Psychologist*, 50:6, 437-447, 1995.
- Andersen, H., MacElveen-Hoehn, P. Gay clients with AIDS: New challenges for hospice programs. *Hospice Journal*, 4:2, 37-54, 1988.
- Aseltine, W.J., Cloutier, M., Smith, M.D. HIV disease and managed care: An overview. *Journal of Acquired Immune Deficiency Syndrome and Human Retrovirology*, 8:Suppl 1, S11-S22, 1995.

Borgatti, S.P. Antbropac **Methods Guide**. Analytic Technologies: Columbia, S.C. 1992.

Brieger, W.R. Pile sorts as a means of improving a quality of survey data: Malaria illness symptoms. **Health Education Research: Theory and Practice**, 9:2, 257-260, 1994.

Butters, E., Higginson, R., Smits, A., McCarthy, M.. Assessing the symptoms, anxiety and practical needs of HIV/AIDS patients receiving palliative care. **Quality of Life Research**, 1, 47-51. 1992.

Carpio-Cedrano, F.F., Bracho de Carpio, A., Anderson, L.. El Programa "Comida para el Pensamiento": Un enfoque participativo en la prevencion del SIDA. **Revista Latinoamericana de Psicologia**, 24:1-2, 137-156. 1992

Case Management Task Force. Case management guidelines and model. Unpublished, 1994.

Cronin, C.J., Maklebust, J. Case managed care: Capitalizing on the CNS. **Nursing Management**, 20:3, 38-47. 1989.

Freire, P. Pedagogy **of the Oppressed**. Continuum: NY. 1970a

Freire, P. Cultural Action and Conscientization. **Harvard Educational Review**, 40:3, 452-77. 1970b

Freire, P. Education as cultural action: An introduction. In Colonnese, Louis M., ed. **Conscientization For Liberation**. Washington, DC: Division for Latin America, United States Catholic Conference. 1971,

Grier, J., Sowell, R.L. Standards and evaluation in community based case management. **Journal of the Association of Nurses in AIDS Care**, Jan-Mar, 1993: 4:1, 32-33.

Gunter, K.S., Joyce, M. AIDS patient writes final chapter of his life - On his own terms. **Caring Magazine**, May, 1993: 12:5, 56, 59.

Holzemer, W.L. Linking primary health care and self-care through case management. **Int. Nurs. Rev.**, 1992, 39:3, 83-89.

Hubert, L., Schultz, J. Quadratic assignment as a general data analysis strategy. **British Journal of Mathematics and Statistical Psychology**, 29, 190-241.

1976

Hubert, L., Schultz, J. Quadratic assignment procedure as a general data analysis strategy. *British Journal of Mathematical and Statistical Psychology*, **29**, 190-241. 1976.

Inhorn, M., Buss, K.A. Ethnography, epidemiology, and infertility in Egypt. *Social Science and Medicine*, **39**(5), 671-686. 1994.

Japsen, B. Better ways to care. *Modern Healthcare*, Oct 3, 24:40, 81-82, 84, 86. 1994a

Japsen, B. AIDS gets managed care approach. *Modern Healthcare*, Oct 24, 24:43, 30. 1994b

Jenna, J.K. New Models for Health Care. *Healthcare Forum*, **30**, 46-48. 1988.

Johnson, S.C. Hierarchical clustering schemes. *Psychometrika*, **32**, 241-253. 1967

Katz, R., Van Maanen, J. The loci of work satisfaction: Job, interaction, and policy. *Human Relations*, **30**(5), 469-486. 1977

Kerson, T.S. Contra Costa County AIDS case management program. *Health and Social Work*, **16**:2, 142-143. 1991.

Kruskal, J.B., Wish, M. *Multidimensional Scaling*. Sage Publications: Newbury Park. 1991

Larkin, H., Koska, M.T., Hudson, T., Eybanks, P. AIDS update: An executive report. *Hospitals*, May, 64:9, 26-34. 1990.

Layzell, S., McCarthy, M. Community based health services for people with HIV/AIDS: a review from a health service perspective. *AIDS Care*, **4**:2, 203-215. 1992.

Layzell, S., McCarthy, M. Specialist or generic community nursing care for HIV/AIDS patients? *Journal of Advanced Nursing*, **18**:4, 531-537. 1993.

Magaña, J.R., Evans, G.W., Romney A.K. Scaling Techniques in the analysis of environmental cognition data. *Professional Geographer*, **33**(3), 294-301. 1981

Magaña, J.R., Ferreira-Pinto, J.B., Blair, M., Mata Jr., A. Una Pedagogia de Conscientización para la Prevención del VIH/SIDA. (Spanish with English abstract) *Revista Latinoamericana de Psicología*, 24:1-2, 97-108. 1992.

McCann, K., Wadsworth, E., Beck, E.J. Planning health care for people with HIV infection and AIDS. *Health Services Management Research*, 6:3, 167-177. 1993.

Morrison, C. Delivery systems for the care of persons with HIV infection and AIDS. *Advances in Clinical Nursing Research*, 28:2, 317-333. 1993.

Philbin, P., Altman, D. HIV/AIDS home care: An HMO experience. *Caring Magazine*, Aug 9:8, 42-45. 1990.

Piette, J.D., Fleishman, J.A., Stein, M.D., Mor, V., Mayer, K. Perceived needs and unmet needs for formal services among people with HIV disease. *Journal of Community Health*, 18:1, 11-23. 1993.

Piette, J., Fleishman, J.A., Mor, V., Dill, A. A comparison of hospital and community case management programs for persons with AIDS. *Medical Care*, 28:8, 746-755. 1990.

Piette, J., Fleishman, J.A., Mor, V., Thompson, B. The structure and process of AIDS case management. *Health and Social Work*, 17:1, 47-56. 1992.

Piette, J., Thompson, B., Fleishman, J.A., Mor, V. The organization and delivery of AIDS case management. The Changing *Face of AIDS: Implications for Social Work Practice*, Eds. V.J. Lynch, G.A. Lloyd, and M.F. Fimbres. Auburn House: Westport, CT. Greenwood Publishing Group, Inc. 1993.

Pirie, L.P., Stone, E.J., Assaf, R.A., Flora, J.A., Maschewsky-Schneider. Program evaluation strategies for community based health promotion programs: Perspectives from the cardiovascular disease community research and demonstration studies. *Health Education Research*, 9(1), 23-36. 1994.

Priority Expert Panel on HIV Infection. *Delivery of Nursing Care: HIV infection: Prevention and Care*. Bethesda, MD: National Center for Nursing Research. 1990.

Romney, A.K., Bachtelder, W.H., Weller, S.C. Recent applications of consensus theory. *American Behavioral Scientist*, 31(2), 163-177. 1987.

Ruebush II, T.K., Weller, S.C., Klein, R.E. Qualities of an ideal volunteer community malaria worker: A comparison of the opinions of community residents and national malaria service staff. *Social Science and Medicine*, 39, 123-131. 1994.

Schull, D.E., Tosh, P., Wood, M.. Clinical nurse specialists as collaborative care managers. *Nursing management*, 23:3, 30-33. 1992

Shepard, R.N. *Multidimensional Scaling: Theory and Applications in the Behavioral Sciences*. Eds, R.N. Shepard, A.K. Romney, S.B. Nerlove. New York: Seminar Press. 1972.

Sonsel, G.E., Paradise, F., Stroup, S. Case management practice in an AIDS service organization. *Social Casework*, Jun, 69:6, 388-392. 1988.

Sowell, R.L., Meadows, T.M. An integrated case management model: Developing standards, evaluation, and outcome criteria. *Nursing Administrative Quarterly*, 18:2, 53-64. 1994.

Twyman, D.M., Libbus, M.K. Case management of AIDS clients as a predictor of total inpatient hospital days. *Public Health Nursing*, 11:6, 406-411. 1994.

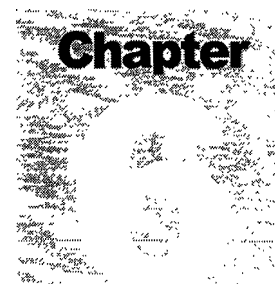
Wallerstein, N., Bernstein, E.. Empowerment education: Freire's ideas adapted to health education. *Health Education Quarterly*, 15:4, 379-394. 1988.

Weller, S.C., Romney, A.K. *Systematic Data Collection*. Newbury Park, CA: Sage Publications. 1988.

Weller, S.C., Romney, A.K. *Metric Scaling: Correspondence Analysis*. Newbury Park, CA: Sage Publications. 1990.

Weller, S.C., Pachter, L.M., Trotter, R.T., Baer, R.D. Empacho in four Latino groups: A study of intra- and inter-cultural variation in beliefs. *Medical Anthropology*, 15:2, 109-136. 1993

Wright, J., Henry, S.B., Holzemer, W.L. Falknor, P. Evaluation of community based nursing case management activities for symptomatic HIV/AIDS clients. *Journal of the Association of Nurses in AIDS Care*, 4:2, 37-47. 1993.



Developing Standards of Practice for HIV Case Management: San Francisco's Model

Myrna Cozen MPH

The San Francisco model of continuum of care services has been lauded throughout the country for its comprehensive approach to chronic care management for people with HIV disease. Although case management has always been a part of the constellation of services offered in San Francisco, it never served as the hub of the HIV service system, as it has in other localities.

In **1994**, the HIV service system for the San Francisco Eligible Metropolitan Area (EMA)¹ was reorganized as part of a comprehensive 5-year plan. In the reconfigured system, currently in the process of being implemented, case management is emphasized as the means to ensure continuity of care for the client, avoid delays in care acquisition, and eliminate duplication of function by many agencies. Because case management is practiced in a variety of forms by HIV service agencies throughout the EMA, it is useful to define another concept. "Care coordination" embraces many of the tasks that program staff informally take on to improve communication among service providers and ease the way for clients to obtain benefits and services.

This paper is the result of an ongoing planning process in San Francisco

. Myrna Cozen MPH is a public health consultant based in Oakland, California.

¹ The San Francisco Eligible Metropolitan Area (EMA) consists of three contiguous Bay Area counties: San Francisco, San Mateo and Marin.

aimed at defining the parameters of and standards for HIV case management and care coordination within the context of a client-centered, comprehensive, and community-based system of care. The paper first addresses the concept of HIV case management. The component tasks, which taken together constitute comprehensive care management, are defined. Next, the paper suggests some approaches for developing outcome and quality assurance measures, units of service, and evaluation strategies. Finally, it discusses the issues involved in the development of documentation and database management systems to support case management programs.

Factors Related to Variation in **HIV** Case Management Practice

The concept of case management for people requiring long-term care has been described in the social work and nursing literature for more than two decades (Benjamin, **1989**). HIV case management was initially derived from models of care for the elderly, the mentally ill, and persons with other chronic and degenerative diseases. HIV case management since has emerged as the primary strategy for coordinating the range of health care, psychiatric, psychosocial, and practical support needs of people with HIV disease (Mor, Piette, and Fleishman, 1989; Pantel, 1991).

As therapeutic responses to HIV disease developed and life expectancy after diagnosis increased, HIV came to be viewed more as a long-term care challenge for the medically well-managed patient. Chronic care models of disease management have been employed both to maintain the independence and quality of life of the person with HIV disease, and to pursue the belief that community-based psychosocial support and nursing interventions would prove cost-effective by reducing hospital admissions and length of stay. In particular, for low-income persons and those who are at the margins of society – by virtue of dual or triple diagnoses of substance abuse or mental health problems – case managers have come to play an increasingly important role. They mediate access problems and allay crisis situations by working as advocates and counselors for their clients.

Case management services -- whether provided by nurses, social workers, or teams of health and social services providers – are designed to assure that clients are appropriately assessed and provided with needed services on a timely basis. Because people with HIV disease are subject to precipitous changes in their health and functional status, they may need assistance in acquiring rapid access to health and social services providers as new needs arise. Working with clients, their families, and caregivers, case managers are

in a unique position to represent the client with other service providers, advocate for the client with legal, financial, and entitlement services, and procure services that may be needed on an emergency basis such as housing, utilities, or transportation.

HIV case management is practiced in a range of settings and comprises a varying array of personal and professional services. The emphasis of HIV case management programs may vary according to the setting, ownership, and professional specialty of the sponsoring agency. Different localities have developed their own responses to the AIDS epidemic that reflect the existing service structure, available financial resources, and the racial and ethnic communities involved. In some communities, case management services are **brokered** by agencies that provide no direct services. In other communities, social service and nursing agencies provide both case management and some or all of the services associated with the HIV continuum of care. Another model relies on umbrella organizations or consortia of HIV-related organizations that band together specifically for the purpose of coordinating care for people with HIV disease. Very often, a combination of practice modalities and sponsoring agencies is involved in a community's response to HIV.

Because case management is practiced by such a broad spectrum of service agencies, there is great variation in substance and style, especially regarding client assessment and follow-up. The need for protocols to guide the practice of HIV case management arises from this variation and is needed to guarantee minimum standard of care regardless of the locus or affiliation of the case management program. Each of these factors, along with professional nursing and social work precepts for client assessment and care, play a role in determining standards of practice for case management.

The functions that case managers traditionally perform include intake and assessment; individualized service planning; referral and system linkage; monitoring service receipt and client status; and adapting the service plan as client needs change over time. The literature examines several paradigms for case management practice. They include the interdisciplinary versus generalist/broker models (Weil, 1985); client-centered versus system-centered (Kane, 1987); the traditional human relations and diagnostic models (Weil, 1985); and the hospital discharge planning, the traditional, the direct care, and gap-filling models (Benjamin, 1989). However, most investigators concur that there is no universally applicable approach. The task for any community planning an HIV case management program is to match target population needs with existing service system components in order to

maximize use of existing resources. At the same time, needless duplication of effort should be avoided.

The comprehensive 5-year plan for the San Francisco EMA develops the concept of care coordination as well as case management. Although that care coordination is not addressed in detail here, it is relevant to note that the San Francisco concept is being used with increased frequency in several localities to denote a system of organizing continuing care that is both broader in scope and more inclusive than case management. In terms of the developing system in the San Francisco EMA, care coordination emphasizes improved communication among providers; a single process of eligibility determination; registration into the system that will not have to be repeated regardless of where the client seeks care; and a coordinated information and referral system. Strengthening care coordination will result in an increased sense of community ownership of the HIV service system, increased cost effectiveness from the elimination of duplication of the registration process, and improved access to services for the client.

Qualifications of Case Managers

The educational and professional qualifications of case managers varies around the country. The New York State Department of Health AIDS Institute recommends that the case manager be a professional, such as a social worker, nurse, physician's assistant, or other qualified person involved in the multi-disciplinary team caring for the client. The authors suggest that case managers be assigned full-time to case management responsibilities in order to increase their accessibility to clients. They also recommend the use of other personnel, such as community health workers or other para-professionals, to assist in performing the functions of case management under the supervision of the case manager. In Detroit, where two community-based case management programs broker most HIV case management services, similar staffing patterns are employed. In Atlanta, social workers, nurses, pastoral counselors, and therapists are included in an interdisciplinary team. In San Francisco, individuals with different levels of training perform all or some of the functions of case management. In developing standards for case management, it is important to define the appropriate levels of staff training required for the performance of various component activities. Trained community health workers may be adequate for performing initial intake, preliminary assessment, and immediate referrals. Complete psychosocial and nursing needs assessments and care planning, however, require social work or nurse training to meet quality assurance standards.

Client Involvement

Increasingly, client involvement in care planning and management is seen in a positive light. Indeed, many case management programs describe themselves as “client-centered,” implying that clients are encouraged to take the lead in determining level of care and in procuring needed services. The client-to-case manager relationship is sometimes viewed as a contract in which the client takes responsibility for specified aspects of his or her care and treatment while the case manager advocates for the client, procures services, and coordinates care among multiple service providers. Solicitation of information and advice from clients is essential if case management guidelines are to reflect the real-life dilemmas faced by people with HIV disease.

During the course of planning HIV case management services in San Francisco, client input is vital at several junctures. For example, clients have pointed out that it is often advantageous to have several case managers at the same time. This is contrary to the premise that it is inherently better to avoid duplication in service. Many clients find it necessary to request assistance from providers at multiple sites in order to procure a needed service. This is especially the case in obtaining effective client advocacy service for help with entitlement programs, utilities, housing, and financial services. Clients also have made planners and policymakers aware that case management is not always wanted. Many clients prefer to “manage” their own cases and their own lives, until such time as they become too debilitated to do so. Clients have indicated that case management should be an option that clients can choose to exercise, but should not be imposed upon them,

Alternative Approaches to Defining Standards of Practice

Guidelines or standards of practice may consist of definitions of each component of case management, such as intake, assessment, and care planning. They can also include proscribed tasks that must be performed in order to meet client service needs in a manner that is timely, appropriate to the current stage of disease progression, and respectful of the client’s integrity. Guidelines also may specify who is to perform such services in terms of professional training. Such standards are intended to guide case managers in their practice so that a case manager can leave the program without adversely affecting continuity of care for the client.

Alternatively, guidelines can be derived for each service type in the HIV care

continuum in order to assure consistency in quality and content of case management assistance in procuring each service needed by the client. The AID Atlanta case management program (Sowell, 1994) provides an example of this second type of guideline. Specific standards are established for housing, substance abuse services, and other services. Standards are defined for high-need and low-need clients. The AID Atlanta model defines:

- the structure and organization of citywide case management services;
- the process of providing those services (assessing need, making a care plan, implementing the care plan, etc.); and
- the outcome in terms of achieving a desired level of service for the client.

Historically, treatment or service outcome measures often are not appropriate for use with clients with HIV disease, because of the progressive and ultimately terminal outcome of the disease. Therefore, the AID Atlanta model stresses the achievement of “process outcomes” in its evaluation strategy. Process outcomes include such measures as how well case managers were able to meet the standards (for instance of making a comprehensive assessment of housing need), rather than whether any particular treatment goal (such as cessation of substance abuse) was achieved for the client.

Still another approach is that of the New York State AIDS Institute. Their standards define the role of the case manager, the professional training required, the tasks involved, and quality assurance mechanisms. They apply to case management personnel from New York State’s designated AIDS service sites, which include hospitals and free-standing clinics. The main emphasis of the guidelines is the integration of inpatient and outpatient care management, regardless of setting. The tasks of inpatient and outpatient case management contain the following common elements: assessment and development of an initial service plan, multi-disciplinary care coordination, crisis intervention, and counseling. Hospital case management discharge planning is coordinated by the case managers. Outpatient case management adds eligibility determination and assessment, with an emphasis on developing linkages and coordination with community-based providers to the above functions.

In San Francisco, where the 5-year plan includes goals, objectives, activities, and evaluation criteria for each of 17 service components, the emphasis on case management standards is to create a minimum, uniform performance standard that can apply in different case management settings located throughout the system. These include substance abuse treatment centers, visiting nurse and hospice programs, psychosocial and practical support

programs, and primary care and specialty clinics. Because case management is practiced in such a wide variety of settings and by a spectrum of personnel that includes registered nurses, licensed social workers, and other community health workers, uniform quality standards assure that clients attending any case management program receive comparable service. Uniform standards of practice also enable the AIDS office to produce replicable and enforceable contract specifications for case management programs; monitor contracts for case management using uniform criteria; and collect data for evaluation and accounting purposes that are comparable across programs. These administrative features will help ensure that case management programs throughout the community are providing comparable content and quality of service. This, in turn, will encourage client use of case management, equalize distribution of services, and strengthen the role of case management as the hub of the HIV service system.

The San Francisco case management standards will include protocols for client registration into the larger HIV service system. With the implementation of uniform registration standards for HIV service programs throughout the system, clients should never need to replicate that process wherever they appear for care or treatment. In addition to streamlining the process for clients, unified client registration data also should facilitate better communication among providers. More effective and rapid client referrals should be the result.

A case management task force has been convened that is comprised of representatives of a cross-section of agencies in the community that provide case management services for people with HIV disease. The task force includes nurses, social workers, program administrators, and clients of these programs. It also includes representatives from specialized service agencies, such as substance abuse programs, primary care clinics, and programs for women and children with HIV disease. The purpose of the task force is to inform AIDS office staff of the ways HIV case management is practiced in each of these varied settings and to advise them on the creation of minimum community-wide standards, quality assurance mechanisms, and outcome measures.

The development of guidelines for HIV case management in San Francisco includes a close review of current practices in the community. The task force is in the process of defining the tasks, problems, quality control issues, and outcome measures associated with each of the case management components described below. Mail and telephone surveys of HIV health service providers also have been conducted to gain a baseline of information about the breadth

and depth of care coordination and current case management practices used in the community. Intake and assessment tools in use throughout the community have been collected and are being reviewed for content and format. In addition, a thorough literature review is being conducted. With this information, a set of guidelines for practice, quality assurance standards, and outcome measures for HIV case management will be developed.

Defining the Component Parts of HIV Case Management

This section describes the five key components of HIV case management: intake; assessment; crisis intervention and counseling; initial service plan; and monitoring, follow-up, and reassessment.

Intake

Intake is the first encounter that the client has with the service system and provides the first opportunity to inform the client of the full spectrum of services available, including case management. Care should be taken in explaining to the client that the system is intended to be client-centered in all aspects; that is, the services are organized to be convenient to clients and are intended to maintain client well-being and independence. Case management is intended to assist the client in procuring the full range of medical, psychological, and social support services available in the HIV services system. The potential advantages to the client of a decentralized system that supports services provided by community-based agencies should be emphasized. Case management services should be offered to the client during the intake process, but the client should not be coerced to participate in these services. It should be emphasized that case management and other care coordination activities are intended to help make services more accessible to clients and to ensure client satisfaction with care.

During the intake process, the client is informed of his or her rights and responsibilities as a participant in the HIV services system. The client also gives his or her consent to participate in the program. Providing informed consent means making sure that the client understands that he or she retains the right to refuse all services.

The information collected during the intake process is the basis for determining program eligibility and for conducting the comprehensive needs assessment to follow. This information includes the verification of the client's HIV status and financial data needed to make a determination of eligibility for CARE-funded programs and needs-based entitlement programs.

The intake worker also will record the client's initial request for services.

Assessment

A complete assessment of medical, psychosocial, and practical support needs most often is performed by a trained nurse or social work case manager. Some components of the assessment can be delegated to paraprofessional staff working under the supervision of case managers. The intake process may include a cursory assessment of need as reported by the client and determined by the intake worker.

Assessment includes the collection of information describing the client's physical and psychological and social status. This includes clinical status, mental health condition, housing situation, home care needs, financial status, and other social and practical support needs. The assessment also includes an evaluation of the client's functional status, that is his or her ability to independently perform essential activities of daily living. These include the ability to bathe and dress oneself, to conduct homemaking chores such as cooking and cleaning, and to accomplish daily errands such as food shopping and traveling to medical or social services appointments. During the assessment, it is also appropriate to include a discussion with the client about his or her knowledge of the means to prevent secondary transmission HIV infection.

During the assessment, it may be appropriate to acquire supplementary information from people in the client's support network, including family, friends, and caretakers. They may participate in the interview with the client and case manager. Other community health workers who are involved with providing or arranging services for the client could also be interviewed. The assessment is an ideal time to clarify roles of various care providers, especially if the client receives services from more than one community-based agency where some form of care management is provided. Optimally, the assessment is an interactive meeting of all involved with the client's care and includes the full participation of the client in making decisions about the types and intensity of services that the client wishes to receive. From the completed assessment, a care plan is devised by the case manager in conjunction with the client and his or her support network.

Community-wide planning is encouraged to design assessment instruments that are suitable for use in a variety of community-based and clinical settings throughout the EMA. By standardizing the assessment tool, a common set of client data to service providers at sites throughout the system can be achieved without having to duplicate the assessment interview or the process

of verifying HIV and financial status.

Crisis Intervention and Counseling

Crisis intervention and counseling should be provided to clients through their case managers or the primary site of care coordination whenever necessary. Often it is a crisis that precipitates the entry of a client into the service system or case management program. The need for such services should be acknowledged and integrated into the care plan.

Initial Service Plan

The development of the care plan begins with the initial intake and continues through the assessment process. It consists of the translation of the information acquired during the intake and assessment into short-term and long-term objectives for the maintenance of the client's health and independence. The service plan includes identification of services, identification of the agencies to provide those services, and of client services and information to be coordinated among service providers. When more than one agency is involved in coordinating the care of the client, the service plan should include agreements by those providers regarding who is responsible for the various components of care. Client participation in the development of the service plan, especially regarding the choice of providers, is encouraged to the fullest extent possible.

In some cases, primary case management responsibility for a client will shift over time from one agency to another. For example, this could occur in the case of a multiply diagnosed patient who receives substance abuse treatment as well as HIV-related services. This also could occur in situations in which the client enters the system through a community-based agency that provides intake and referral services, but does not provide comprehensive case management. In such cases, the service plan should document which agency has agreed to assume case management responsibilities and the time at which any changes in responsibility are expected to occur. In particular, each agency involved in care coordination for a client should have a clear understanding of who is responsible for monitoring and follow-up care. This information should be documented in the service plan.

Monitoring, Follow-up, and Reassessment

Monitoring and follow-up are related to reassessment. Monitoring is necessary to ensure that clients receive the services initially requested and specified in the care plan.

Reassessment should be conducted periodically to update service needs and available support systems. A reassessment should be undertaken whenever there is a significant change in the client's clinical or psychosocial status. The reassessment should address what progress has been made in meeting the client's service and care needs as identified in the initial care plan. All providers involved in care coordination and service provision for the client should be contacted during reassessment.

Reassessment is often difficult to achieve for case management programs that service large numbers of clients. In such cases, intake, assessment, and response to client requests take up most available staff time, leaving little or no time for reassessment and follow-up. Standard of practice protocols should address the need for periodic reassessment and suggest ways for case management programs to determine optimal caseload size and balance intake and initial assessment with subsequent follow-up activities.

Replication and Enforceability of Standards

The ability to replicate and enforce case management standards will stem from how closely the standards reflect actual clinical practice. Many HIV case management programs have evolved over the years by responding to changes in funding mechanisms, client demand for services, resource availability, and the structure of the local health and social services system. If standards are superimposed on existing service programs that do not reflect current community norms, they are less likely to be applied uniformly or to be enforceable. The purpose of such standards is to ensure a minimum level of quality, consistency in contractual program objectives, and continuity of care for the client.

Units of Service

Many HIV case management programs throughout the country are funded through Title I or Title II of the Ryan White CARE Act. Programs receiving these funds through Federal, State, or local health jurisdictions must account for their contractual obligations by reporting the units of service delivered. Considerable confusion has arisen over the definition of this term. In some localities, the contracting agency defines the term; in others, individual service agencies interpret the unit of service to fit their own service type. Some programs identify these units as deliverables, such as one primary care visit; others identify these units in terms of time, such as how many 1-hour increments of service were delivered in a given contractual period.

If units of service are to be a useful measure of productivity for the continuum of services associated with HIV care – and for case management in particular – then it is necessary to adopt a standardized definition for this term. At present, many providers consider units of service nothing more than an administrative necessity. If units of service are only a measure of staff time spent on contract-related work, they are unlikely to reflect any real measure of program activity. Ideally, units of service should provide an added tool for program administrators to use in planning resource allocations and setting program goals and objectives.

Defining units of service for HIV case management is not a simple task because of the varied nature of the work. While case management might be defined as the full set of activities ranging from client intake through long-term follow-up on a daily basis, case management program staff time might be spent largely on responding to client requests for information and referral, conducting assessments, making home visits, etc. Therefore, units of service must be flexible enough to account for time spent in each of these varied tasks. Tracking these tasks needs to be done as seamlessly as possible in order to fit into the daily operations of the service program. Service agencies that provide both billable and non-billable services, such as primary care clinics and home health or visiting nurse programs, need to be able to track billable units and units of service within a single data collection system.

Evaluation of HIV Case Management Programs

Beginning in the late 1980s, researchers from Brown University evaluated a series of HIV health services programs funded by the Robert Wood Johnson Foundation. The evaluation emphasized the role of case management (Mor, 1989). The researchers studied the structure and function of AIDS case management programs in different service settings, including hospitals and community-based agencies. Although standards of practice per se are not presented, the Brown team did describe client preferences in terms of program type, accessibility, frequency of contact, and other criteria (Fleishman, 1991).

The researchers characterized HIV care coordination programs in terms of organizational type, affiliation, size, staffing patterns, and components (such as tasks performed). They found that the type of tasks performed differed depending on the type of organization and its sponsorship. For example, community-based case management programs tended to emphasize the delivery of emotional, practical, and psychosocial support services, while hospital and clinic-based programs tended to emphasize medical care

management and triage.

Other studies of HIV case management use the San Francisco model to define the continuum of services and describe different approaches to care coordination. These studies often try to demonstrate that centralized care management, combined with appropriate use of this continuum, will result in averted hospital stays and lower overall costs of care, while at the same time making a substantial improvement in the overall quality of life of the client (Cruise, 1993). Recently, studies have begun to question the premise that HIV case management will result in cost savings, long a selling point for these services with funders. Case management and care coordination for people with HIV disease are increasingly being seen as positive in their own right and not just for their cost saving potential.

Evaluation of HIV case management programs can reflect a client-centered approach. The primary goal of evaluation of HIV case management programs should be to determine how well the program is functioning for the client. From the point of view of the client, the most important feature of a case management program is that the case manager acts decisively and effectively on the client's behalf. Clients assembled in focus groups and participating in the San Francisco HIV case management task force have expressed their frustration at the need to "shop around" until they find the case manager or other service provider who is able to help them obtain the benefit they need, find appropriate housing, or secure child care. Building rapport and trust between the case manager and client also is essential to making the relationship work. Evaluation strategies could focus on determining the factors related to interpersonal styles that facilitate the client/case manager relationship.

Other more traditional evaluation activities, such as chart reviews and activity logs, can be used to good advantage, especially if carried out in an experimental context. Because HIV case management programs are engaged in a process of self-definition, variations (on such matters as staffing patterns, intake and registration protocols, length of time to case manager-initiated follow-up, and other clinical practices) can be tested against a normal practice pattern to determine which variation offers the most efficacious outcome for the client or the most cost-effective practice for the program. Creative use of evaluation designs offers HIV case management programs the opportunity for continuous growth and change to respond to the changing needs of their target populations and the changes in health and social service funding and resource allocation.

Defining Outcome Measures

The development of standards and guidelines for HIV case management also includes defining specific measures that can be used for quality assurance, program evaluation, and contract monitoring purposes. The progressive and ultimately terminal nature of HIV disease makes outcome measures difficult to define for HIV case management. Therefore, process measures also should be considered. Examples of processes involved in conducting case management include developing a relationship of trust and mutual respect between case manager and the client as well as effectively involving the client's family and caregivers in care planning, when appropriate. Such interpersonal processes contribute to the success of case management for certain clients.

Where clients are in advanced stages of disease or may be dually or triply diagnosed with substance abuse or mental health problems, traditional outcome measures are likely to be inappropriate. Traditional measures of the outcome of referral to services might focus on whether a particular treatment or service was successful in improving the client's condition, such as achieving drug or alcohol abstinence after enrollment in a substance abuse treatment program. A more appropriate measure of HIV case management outcome might focus on whether the goal of entering the client in a culturally appropriate drug treatment program was accomplished in a timely fashion. It may be more appropriate to measure the time it takes for identified services to be procured, the frequency of follow-up with the client, and client satisfaction with services, rather than whether a particular curative or palliative effect of treatment or services was achieved.

Developing Quality Assurance Standards

The following six indicators should be considered in developing standards for HIV care coordination programs, whether they are full-service case management programs or programs that offer elements of care coordination, such as information and referral.

Frequency of Contact with the Client

In some care coordination programs, client contact is initiated by the client. In others, standards are set for minimum client contact initiated by the case manager (for instance, once per month). Frequency of contact also will depend on caseload size, the type of service program, the level of care required by the client, and client preferences regarding the initiation of contact. In one study of HIV case management programs in Detroit (Study

of Southeastern Michigan Care Coordination for Persons with HIV Disease, 1993), it was found that some clients preferred to initiate contact with their case managers rather than have the case managers contact them on a regular basis.

Mode of Client Contact

Depending on program goals and the needs of the target clientele, different modes of client contact may be appropriate. In some dedicated HIV case management programs that focus on brokering services for their clients, an initial face-to-face intake and assessment will be conducted. After the initial assessment, most client contact takes place over the telephone. However, sometimes the client comes to the site of the case management program to obtain assistance with applications for entitlement programs or to acquire such items as transportation vouchers. The Brown University study found that case managers rarely make home visits because of the time constraints of managing large caseloads (Mor, 1993). While telephone contact may suffice for making referrals, in-person contact may play the dual function of providing the client with social and emotional support and providing the case manager with the opportunity of informally reassessing the client's psychosocial and physical health status.

When care coordination programs are situated within larger HIV service programs, client contact with the case manager at the service site may take place as a natural extension of participation in other program components, such as social support groups, adult day care, or drug treatment.

Caseload Size

Growth occurs rapidly in most HIV case management programs. Establishing optimal caseload sizes and preventing caseloads from growing too large are problems that beset many HIV case management programs. In programs offering comprehensive case management, optimal caseloads of 50-65 clients per case manager have been suggested (Piette, 1992). Most programs have tried to accommodate to the demand, but some have found that it is necessary to cap new enrollments in order to preserve quality. One study suggests that high caseloads arise, at least in part, from lack of adequate triage policies (Mor, 1993). This same study concluded that in the absence of a formal triage system, "clients have been implicitly triaged as case managers devote more time and effort to the most needy clients." The study recommended developing triage protocols that target clients in a way that allocates program resources according to the specific level of client needs.

Relationship of Location of Service Site to Types of Problems

Previous studies indicate that the type of help requested from the case manager or care coordinator will be a function of the location of the case management program. Mor found that clients requesting assistance from case managers located in community-based organizations were more likely to request help in obtaining entitlement, medical care, emotional support, legal assistance, and housing. In contrast, clients whose case managers were located at a medical clinic were as likely to request assistance with obtaining entitlements, but were far less likely to request assistance with housing, medical care, or emotional support.

Tasks Performed by Case Managers

Because HIV case management is an emerging field, and health and social services providers from multiple disciplines are involved, the tasks performed by case managers are not always the same. Care coordination is a broader concept that includes more informal means of client care management, such as information sharing, service referrals, and advocacy for the client with legal, financial, or social services institutions. Case management usually refers to services performed by professionally trained nurses or social workers. Formal case management usually involves comprehensive assessment and care planning as described above. Whatever the mode of delivery of care coordination, an appropriate spectrum of activities should be defined for each type of service provider.

Outcome Measures for Evaluating Successful Case Management

In measuring the effectiveness of case management for people with HIV disease, it is important to consider realistic outcomes. The goals of HIV case management are to maintain or improve the client's ability to remain independent in his or her home environment, and to maintain or improve quality of life for the client during the course of his or her illness. In order to accomplish these goals, successful case management must ensure that the client actually receives the services for which he or she is referred, that periodic reassessments of the client's status are conducted to update the care plan, and that adjustments in the configuration of services are made to accommodate to changes in health or social status. Evaluation of case management services must include measures of the successful accomplishment of these components.

Documentation

At a minimum, documentation of case management services should include:

- an initial intake or registration form, taken at the time of first client contact;
- the request for services;
- an initial assessment of client status and service needs; and
- the initial care plan specifying the services to which the client is being referred and the manner in which the referral will take place.

Documentation should include the name of the case manager or care coordinator and, if relevant, indication of whether other case managers, working out of other service sites, are involved with the client. When multiple case managers are involved, the care plan should indicate how coordination of efforts will take place. Documentation should include the date of encounter with the client; the date of service referral; the date of service delivery; the name of the person or agency providing the referred service; and information indicating whether the service requested was received.

The development of care coordination for the San Francisco EMA includes the creation of a database management system (discussed below). This system will be implemented in phases over the next 5 years. The first phase involves the development of systemwide intake and service referral/request forms that will be available online at all service agencies providing case management in the EMA. This will facilitate communication among agencies and expedite the process of procuring services for clients.

Data collection for the purposes of monitoring client enrollment and utilization of services across the continuum must be set up to ensure unduplicated case counts. Some form of patient-specific identifier needs to be developed to allow providers to track unduplicated client enrollment, requests for services, and service utilization across sites. The patient identifier does not need to include the patient's name, social security number, or other identifying information that could violate confidentiality. Rather, it only needs to be a combination of letters and numbers that are unique to the patient within the HIV services system. This algorithm does not need to be linked to patient medical, financial, or other social services identifiers.

Development of Database Management Systems

Database management systems for HIV case management and care coordination programs need to provide:

- an information bank and conduit that facilitates one-time-only entry into the system from any CARE-funded service site;
- access to a continuously updated, online resource directory that will serve as a guide to services for clients and providers;
- the basis for building a comprehensive client-level database for assessment of health status and care needs, care planning, and a record of service referral.

As patient caseloads grow, agencies that coordinate the care of persons with HIV disease are turning to computerized database management systems to keep track of patient flow into and out of the programs. The need for reliable data is heightened by the requirements of the Federal Government and other funding agencies. CARE-funded programs are required to produce aggregate data that describes the volume and type of services on a **program-**by-program level for the entire service system. The collection of **system-**wide, client-level data would allow planners and evaluators as well as program managers to gain an accurate picture of program utilization, including the distribution of clients among service programs.

For multi-agency systems, reliable data are required for program management, contract monitoring, and client tracking. To meet these requirements and enhance program efficiency, a database management system should collect and report patient demographic and baseline health status data, absorb changes in medical and social status, identify areas of critical need, and indicate the type of follow-up services needed.

Selection of a Database Management System

Whether simple or complex, any database management system that is developed to facilitate the work of client care coordination within a single agency and across agencies within a community must involve the end users as collaborators in the development of that system. The primary objective of this approach and of the system itself should be to empower the end users (the direct service providers at each of the CARE-funded service sites) to develop solutions for the care needs of their clients and for their own information needs with a minimum of help.

If community-wide standards for HIV case management are to be effectively

implemented, then a specific set of data collection and management objectives will be shared by programs throughout that community. These include the need to document:

- . the number of people served (for local program monitoring and to comply with HRSA's Uniform Reporting System);
- demographic, medical status (specifically HIV status), and financial data of their clients; and
- the service needs identified and the service programs to which the clients have been referred.

Ideally, a database management system for HIV case management and care coordination should collect and report client data and update records when changes occur in medical and social status (including changes in financial status or insurance coverage). This is a complicated task and HIV service systems throughout the country have turned to complex, pre-packaged systems to support these functions. Most of these systems rely on local area networks that support a variety of MS-DOS applications. Some are based on a client/transaction model that consists of two levels of data: 1) data that do not change over time (such as client name, birth date, or date of diagnosis), and 2) data that can or will change over time (such as functional status, services being used, the care plan). However, alternative systems can be developed that are more flexible in adapting to changing program needs and practices. These software systems would not be written in a proprietary language, but would employ a standard file format, and allow users to add data items and modify entry screens as needed.

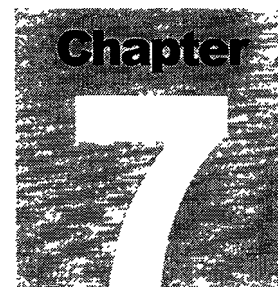
Perhaps the most important point to be made when proposing a database management system for a health and social services system as vast and complex as those found in the major HIV epicenters is that the development of such a system should involve the system end users. In other words, the case managers and other front line people who interact directly with clients should determine their need for service, conduct the online research required to locate appropriate and available services, and make the referrals. Whether the end users perceive the database management system as a help or a hindrance in their work ultimately will determine the success of that system.

References

- Benjamin, A.E. Perspectives on a continuum of care for persons with HIV illness. National Center for Health Services Research and Health Care Technology Assessment (NCHSR) Program Note. Rockville, MD: US. Department of Health and Human Services, 1989.
- Benjamin, A.E. Long-term care and AIDS: perspectives from experience with the elderly. *The Milbank Quarterly* 66(3):415-443.
- Cruise, P.L. and Liou, K.T. AIDS case management: a study of an innovative health services program in Palm Beach County, Florida. *JHRA* (Summer 1993): 96-111.
- Fleishman, J.A., Mor, V., and Piette, J. AIDS case management: the clients perspective. *HSR: Health Services Research* 26, no.4 (1991):447-469.
- HIV Health Services Comprehensive Five Year Plan: A Client-Centered System of Care. San Francisco HIV Health Services Planning Council, February, 1995.
- Kane, R.A. and Kane, R.L. Long-term care: principles, programs, and policies. Springer Publishing Co., Inc.: New York, NY, 1987.
- Mor, V., Fleishman, J. A., Piette, J.D., and Allen, S.M. Developing AIDS community consortia. *Health Affairs* (Spring 1993): 186-199.
- Mor V., Piette, J. and Fleishman, J.A. Community-based case management for persons with AIDS, *Health Affairs* 8(4)(1989):139-53; 1989.
- New York State Department of Health AIDS Institute: Designated AIDS center case management guidelines, September 1994.
- Piette, J.D. et al. The structure and process of AIDS case management. *Health and Social Work* 17(1)(1992):47-56.
- Sowell, R.L. and Meadows, T.M. An integrated case management model: developing standards, evaluation, and outcome criteria. *Nursing Administration Quarterly*, 1994: 18(2):53-64.
- Study of Southeastern Michigan Care Coordination for Persons with HIV Disease in the Non-Acute Care Setting: Final report of the Resource for

Public Health Policy, School of Public Health, University of Michigan,
September 1993.

Weil, M., Karls, J.M. et al. Case management in human service practice.
Jossey-Bass Publisher: San Francisco, CA, **1985**.



A Cooperative Model of HIV Case Management: Evaluation and Research Issues from Chicago

*Paul L. Kuehnert MS RN, Terrie Matthes MA CRADC,
and William L. White MA.*

Case management in the HIV service arena denotes a number of models of practice performed by people with a variety of educational backgrounds (Land, 1992; Mor, Fleishman, Allen, and Piette, 1994; Sowell, 1995). The interagency, cooperative model of case management described here is based on the belief that strong community partnerships and coordination can reduce the fragmentation that characterizes health care and social service delivery (White, 1994). Such partnerships can yield high-quality, cost-effective care (Sigmond, 1995).

To better understand HIV case management, this article describes and analyzes the client-focused, interagency collaborative model of HIV case management we developed and have implemented over the past 6 years at the AIDS Foundation of Chicago (AFC) (White, 1994).

First, we describe the evolution of the HIV epidemic in Chicago and the response of health and social service providers to it. Next, we present the conceptual foundation of our case management model, its development over time, and systems-related outcomes to date. Last, we present the current and future issues facing our collaborative partnership and their implications for the development of a case management evaluation and research agenda.

*The authors are with the AIDS Foundation of Chicago.

AIDS in Chicago

Chicago is a so-called second-wave city, hit later than the coasts by the AIDS epidemic. However, by the **mid-1980s**, Chicago's health and human service agencies were being challenged to address the special needs of people with AIDS or infected with HIV. Because many health care agencies feared and shunned persons with HIV, community-based organizations emerged to address the needs of those affected. Many of the initial efforts were made by volunteers who themselves were infected with HIV. Over time, practitioners at Chicago's major medical centers began to develop specialized programs. Slowly, both new and traditional agencies addressed HIV-related education and care issues. In **1985**, the AIDS Foundation of Chicago was created to coordinate these efforts. Four years later, the Northeastern Illinois HIV/AIDS Case Management Cooperative was established to coordinate the delivery of case management services to persons with HIV.

The AIDS Foundation was organized by civic leaders and health professionals. Since its founding, the organization has worked to develop and support a comprehensive system of HIV prevention and care. It also brings together public and private resources to fight the epidemic, advocates for sound and compassionate AIDS policies, coordinates the activities of local service providers, and presses for involvement of all sectors of the community.

AFC's operations are managed by a **35-member** corporate and civic board of directors. AFC policy and program priorities are determined by the board in partnership with a Service Providers Council that has grown to include more than **120** member agencies. The partnership between the board and the Service Providers Council ensures that AFC's programs are grounded in the actual experiences of those working on the front lines of the AIDS epidemic.

Development **of** HIV Case Management in Chicago

In the fall of **1988**, AFC received funding for a service demonstration project from the Federal Health Resources and Services Administration (**HRSA**) to develop an area-wide case management system. First-year objectives included convening a case management task force, sponsoring a working conference on case management, and expanding an existing case management experiment aimed at homeless and hard-to-place clients. Within that first year, four case management positions were funded at three agencies in Chicago.

From the beginning, a conceptual framework based on community organization and community development guided the development of the case management cooperative. Community organization has been defined as “human services activities that focus on broader social approaches to human betterment, emphasizing such things as developing enlightened social policy, organizing the effective delivery of services, strengthening community life, and preventing social ills” (Rothman and Tropman, 1987). In this framework, the active involvement of community members in problem solving is valued and the process of organization, activation, and change is viewed as a part of the outcome (Ross, 1967).

Our case management task force explored how to best respond to the growing epidemic, analyzed a variety of issues and concerns, and developed a service model that conceived of a consortium or cooperative of agencies guided by elected agency and consumer representatives and linked by administrative and support services. The Coop, as it came to be known, was established in July 1989 and initially had a very elaborate committee, subcommittee, and regional caucus structure. This structure, along with a similarly elaborate set of bylaws, was seen as a vehicle to ensure geographic accessibility, cultural sensitivity, and responsiveness to the special needs of specific populations. They also formalized a degree of autonomy for service providers who were entering into a new sort of relationship and were mistrustful of “bigness” and centralization while establishing a means of coordination and cooperation.

The case management model and its ultimate success came in the crucible of service delivery practice. Four elements were – and remain today – crucial:

- Meaningful provider leadership and participation;
- Staff leadership;
- Adequate resources and their equitable distribution; and
- Centralized training.

Provider participation and leadership

Service provider participation and leadership began with the convening of the case management task force that ultimately gave shape to the cooperative model. The governance and bylaw structure devised for the cooperative provided early assurance of a partnership approach by and between the Foundation and the providers. Service provider involvement in the operations of the cooperative during its first few years gave substance to the partnership. Major decisions included hiring the Foundation’s first case management coordinator, discussion of area-wide service needs, and review

and approval of proposals for case management service contracts. Since then, executive directors and middle managers from a wide variety of case management agencies consistently have played an active role in the cooperative's governance. More recently, the group dropped the elaborate cooperative governance structure and a case management governance committee was established in its place. This committee, now one of the standing committees of the Service Providers Council, has a greater focus on policy development and review than on operations. One example is quality assurance.

Central staff leadership

Crucial to active provider involvement in our collaborative model is leadership from the "central staff" of the case management cooperative (the program staff of the Foundation). In the cooperative's formative years, the staff was very small – first one, and then two persons – and the personal and professional attributes of the program director were key. These attributes included openness, commitment, integrity, enthusiasm, and extensive theoretical and practical knowledge of community organizing, group dynamics, case management, and HIV. To be effectively practiced by any staff member, these attributes must be found in and supported by the organizational culture of the coordinating agency, as has been the case at the Foundation. The fostering of such a culture has remained a deliberate commitment throughout the cooperative's development. Five key principles govern our foundation-provider relationships: mutuality, honesty, respect, responsiveness, and support. We strive to conduct all our relationships in the cooperative on these principles, principally in governance, among providers, and between the Foundation and individual providers.

Resources

Before case management services could be delivered to clients, resources had to be obtained and then distributed. The distribution of resources was based upon an assessment of the need and demand for case management services in different community areas and agreement regarding which tasks would be centralized and which based in the community. Hence, the third crucial factor is adequate resources and their equitable distribution. Fortunately, as shown in Table 1, we have been building the case management cooperative in a period of growing resources, although those days may be over.

In addition, even though the growing resources have not kept pace with the absolute growth of the epidemic in Chicago, they have kept pace with the ability of service providers to "grow" their programs. Although we will soon look more specifically at the distribution of resources, in general, resources

have been adequate to allow for a mutually agreed on division of labor (see Table 2).

Table 1 Chicago Case Management Allocations 1991-1995¹					
Source	1991	1992	1993	1994	1995
Title I	\$ 634,000	\$ 813,500	\$ 1,502,653	\$ 2,882,763	\$ 2,948,015
Title II	\$ 262,176	\$ 302,985	\$ 390,523	\$ 504,575	\$ 565,000
DORS	--	--	\$ 432,200	\$ 776,627	\$ 842,567
Total	\$ 896,176	\$ 1,116,485	\$ 2,325,376	\$ 4,163,965	\$ 4,355,582

Table 2 Case Management Cooperative Structure and Functions	
AIDS Foundation of Chicago Staff	Direct Service Agencies
Solicit, administer, and report on funds	Outreach and case finding
Maintain central client registry	Direct service delivery
Central information and referral service	Clinical supervision
Case manager training and technical assistance	Reporting
Support structures for case manager participation	Governance
Staff support for governance	

Central training

The fourth but far from least crucial factor in the development of our collaborative model has been the establishment and maintenance of a centralized training program for case managers. The need for such a program grew out of practical concerns for efficiency in orienting and updating a growing, diverse group of case managers. The value of centralized training, however, has extended far beyond its initial training purpose to provide group identity and support for the case managers. This expansion of the program was deliberately shaped by the program director and completely supported by the governance and individual provider management teams.

Our focus has been to develop a common ground based on a common language and core values. These core values (client-centered and life-focused, focusing on client strengths, and striving to maintain autonomy, respect, compassion, flexibility, spirituality, and caring) have been woven through our case reviews as well as our more topical and informational trainings. The

¹ Ryan White CARE Act Title I and Title II and Illinois Department of Rehabilitation Services (DORS) waiver.

core values provide the contextual framework for HIV case management practice in Chicago.

Outcomes of HIV Case Management in Chicago

In order to be accurate and useful, evaluation of the process and outcome of HIV case management must be directed to the “systems” level and the individual client level. Furthermore, evaluation must be conducted in the context of serving a client population that not only has a chronic, debilitating, and fatal illness but that presents with a web of additional social and health problems. Table 3 summarizes the complexity of issues facing this client population.

Table 3 Self-Reported Psychological Problems Among a Sample of People with HIV in Chicago ²	
Problem	Percent Reporting
Current substance use	42 percent
History of incarceration in jail or prison	37 percent
History of homelessness	43 percent
Income of less than \$6,000 per year	49 percent

In addition to these problems, currently about 40 percent of case management clients have no source of payment for medical care at the time of intake. We must evaluate our efforts keeping these contextual factors in mind. We have gathered preliminary information regarding access, linkage with, and utilization of other services, cost effectiveness, and client and provider perceptions regarding the adequacy of services.

Access

The case management cooperative has grown from 3 agencies and 4 case managers in 2 sections of Chicago in 1989 to 56 agencies and 82 case managers in every area of the city and throughout the 9-county suburban region. Providers have been concentrated in areas where the epidemic is most concentrated, while maintaining geographic access throughout the region. We also have ensured the participation of culturally and linguistically appropriate providers as well as multiple service providers.

Table 4 shows that the number of clients served has increased each year, proportional to the increase in resources. We estimate that we are now

² Respondents to the Chicago EMA HIV/AIDS Housing Needs Assessment Consumer Survey, AIDS Foundation of Chicago.

serving approximately 10 percent of the entire population of people living with HIV infection and approximately 35 percent of those living with AIDS.

Table 4 Unduplicated New Case Management Clients Served in the Chicago EMA 1991-1995					
Source	1991	1992	1993	1994	1995 ³
Title I	892	1,060	1,690	2,513	476
Title II	NA	NA	564	300	57
DORS	NA	NA	760	1,102	1,219
Total	892	1,060	3,014	3,915	1,715

Table 5 indicates our cumulative service statistics (since 1993); they reveal over-representation of women and racial minorities, as one might expect given the disproportionate impact of poverty and other social problems on women and people of color. The demographic profile of current clients shows a continuation of this trend, although the racial/ethnic characteristics of our clients more closely match those of the emerging cases of HIV, as shown in Table 6.

While access to case management services is important, a key function of case management is to assist clients in gaining access to other services. To date, we have not captured comprehensive, reliable data regarding referrals and service access. Reviews of quarterly reports from Title I and II contractors for medical, housing, mental health, and drug treatment services indicate that approximately 38 percent of new clients come to these providers by way of case manager referrals (Wolf, 1995). The food service provider reports that more than 95 percent of new clients come to the agency from case managers (Miner, 1995).

In 1994, 103,937 case management service encounters were provided by Coop case managers to 2,813 unduplicated clients. In that same year, 33,253 taxi rides were provided to transport clients to medical and social service appointments that were arranged by Coop case managers and paid by Title I funds. These data indicate that case managers are providing services to clients and that at least one concrete need – transportation – is being met. Anecdotal reports by clients and case managers and a study of the use of Ryan White CARE Title I funds in the Chicago area indicate that we have

³ Data from Title I and Title II are first quarter only.

created an accessible case management system that successfully opens doors to other needed services (Winkle and Carr, 1995).

Table 5 Cumulative Case Management Client Demographics and Cumulative AIDS Cases in Chicago		
Characteristics	Cumulative Case Management Clients	Cumulative AIDS Cases
Gender		
Male	76%	88%
Female	24%	12%
Ethnicity		
African American	51%	48%
Caucasian	29%	38%
Latino	20%	14%
Other	--	--
Risk Categories		
Men who have sex with men	34%	59%
Intravenous drug user	26%	25%
Heterosexual	23%	8%

Table 6 Case Management Client Demographics and 1994 Reported AIDS Cases in Chicago		
Characteristics	Case Management Clients	1994 AIDS Cases
Gender		
Male	73%	85%
Female	27%	15%
Ethnicity		
African American	52%	56%
Caucasian	26%	28%
Latino	20%	15%
Other	2%	1%
Risk Categories		
Men who have sex with men	30%	48%
Intravenous drug user	27%	34%
Heterosexual	24%	15%

A key component of the HIV service system in the Chicago area is the Home Services Program of the Illinois Department of Rehabilitation Services (DORS). Administered in the Chicago area by the Foundation, DORS is funded through a Medicaid waiver with the explicit purpose of shortening

hospital stays and avoiding unnecessary institutional placement. It can be accessed through case managers, health care providers, family members, and hospital discharge planners. To qualify for services, clients must be Medicaid eligible, disabled, and in need of assistance with activities of daily living. The program pays a monthly fee for case management, and up to \$3,600 per month for in-home assistance with personal care and household chores.

Clients receive services for an average of 6 months, with the overwhelming majority of discharges due to death. One measure of successful access to this program is the number of DORS clients in a given year as a percentage of those estimated to be living with AIDS during that year, as shown in Table 7. This crude measure probably indicates the minimum percentage of eligible persons with end-stage HIV disease who have accessed the program. The percentage is a minimum because not all people with a diagnosis of AIDS need the service or are sufficiently disabled during a given year to meet the eligibility criteria.

The upper end of the percentage of eligible persons served by this program may be established by comparing the number of unduplicated clients with the number of AIDS deaths in a given year. This calculation would be based on the assumption that those who die during a given year would be sufficiently disabled during that year to qualify. During the one year for which we have data (1993), 760 unduplicated clients received DORS services and 981 persons died of AIDS in Chicago. Thus, the Coop may have served up to 77 percent of those eligible for the program in 1993.

Cost Effectiveness

Utilization data from the past 3 years indicate that, on average, clients using the DORS home services program purchase about 30 hours of care each week from a homemaker or personal attendant along with their case management services. As shown in Table 8, average costs are about \$1,000 per month.

As illustrated in Table 9, this service arrangement is cost effective compared to long-term care provided in either nursing homes or HIV-specific congregate housing settings. It remains cost effective for end-stage clients even when the DORS service cost is taken to its maximum and “enriched” with food services and rent subsidy services.

Table 7 Chicago EMA DORS Clients Compared to Estimated Total AIDS Cases			
Year	DORS Clients ⁴	Estimated Total AIDS Cases ⁵	Percent
1993	760	2,800	28%
1994	1,102	4,000	28%
1995	1,219	5,100	24%

Table 8 1995 Service Costs for Persons with HIV Disease in the Chicago EMA	
Service Unit	Cost Per Unit
Case management for one month	\$ 75.00
Food pantry meal equivalent	\$ 2.00
Home delivered meal equivalent	\$ 5.50
Rent subsidy for one month	\$ 375.00
Congregate housing day	\$ 80.00
Hospice day	\$ 140.00
DORS home service month	\$ 1,060.00
Long-term day care	\$ 100.00

Table 9 Cost Effectiveness of Case Management: Hypothetical Comparisons	
Service	Monthly Cost
Case management and 30 hours per week in home assistance	\$ 1,060.00
Above, plus rent and food subsidies	\$ 1,495.00
AIDS assisted living facility	\$ 2,400.00
Long term care facility	\$ 3,000.00

At the current average Medicaid payment of \$450 per day of hospitalization for a patient with an AIDS diagnosis in Illinois, shortening a hospital stay by 2 days pays for nearly a month of home services and case management. We believe, on the basis of anecdotal information, this service is shortening hospitalizations although we do not currently have data to support our belief.

⁴ Unduplicated

⁵ Estimated by Chicago and Cook County HIV Services Planning Council

Neither do we have conclusive data regarding the cost-effectiveness of **non-DORS** case management. We believe that, at an annual cost of roughly \$900 per client, the shortening of one hospitalization or the avoidance of **long-term** institutionalization by providing home services effectively pays for this service. However, we also recognize that case managers in our model are “gate-openers” (not gatekeepers), increasing the utilization of resources by our clients. Some of these services and their associated unit costs are shown in Table 9. Again, data supporting a positive cost-benefit ratio to general case management have not been gathered and analyzed.

Service adequacy

We do have limited information regarding the perceptions of both clients and providers regarding the improvements in access to case management services over the past 4 years. We also have information regarding client perceptions of the adequacy of services.

In an evaluation of the use of Title I funds in Chicago, clients and providers were asked to compare ease of access to case management in 1994 to that in 1990 (Winkle and Carr, 1995). The overwhelming opinion of both groups was that access had become much easier. In addition, 72 percent of the 224 individuals with HIV interviewed stated that they received an adequate amount of case management services.

Current and Future Issues

As our collaborative partnership enters its seventh year of practice, we face many significant issues. These issues have a direct bearing on questions regarding program evaluation and outcomes research that we believe must be addressed.

The key issue facing us is long-term survival – not simply survival as a response to the urgent demands of an emerging epidemic but survival as a maturing organizational form. To survive in these ways we must successfully grapple with four related issues: growing demand, limited resources, identity, and quality.

Growing demand is self-evident in serving our target population. However, not only does the epidemic of HIV infection continue to grow quantitatively, it is changing and growing qualitatively in a way that affects the provision of case management and other social services. One of the qualitative changes is the increasing impact of the epidemic on those already on the margins of our society: the addicts, the very poor, the homeless, and people of color. A

second qualitative change is the continuing advances in medical treatment that increase the length of survival of persons with HIV infection.

This increased demand is taking place within the context of shrinking resources for providing services. This decrease in resources is due to an increasingly hostile political environment that already has flattened the growth of public resources for prevention, care, and research. It also stems from changes in the health care industry itself as cost-consciousness and control measures – while having had some salutary effects on a system run amok – increasingly drive care-related decisions. Market forces alone will not “fix” the health industry and, in the meantime, can do tremendous damage to safety net systems for vulnerable populations.

The growing demand for services in an era of shrinking resources forces us to examine and further define our identity as a collaborative service entity. For example, we have collectively valued each provider’s organizational autonomy in defining case management and its practice within diverse communities. We now face increasing pressure to standardize case management from organizations competing and clients demanding equity across a larger system.

Another identity issue concerns the general model of case management used in the cooperative: we are based in a social work model which seeks to provide information, support, and advocacy and to increase access to community resources, including medical care. This model differs from the increasingly common medical case management model, which focuses nearly exclusively on gatekeeping functions related to the use of medical services. Market forces-particularly Medicaid reform-are forcing us to come to terms with the medical case management model. We must either find a way to incorporate it into our approach and structure, operate alongside it while strictly defining “turf,” or cease doing case management.

Intertwined in the issues of identity and our response to the demand-resource dynamic is the issue of the quality of the services we provide. We are in the early stages of developing a quality assurance-quality improvement program. We are seeking to measure quality and quality improvement by looking at both process and outcome indicators. We are now developing a benchmarking approach to monitoring and reporting quality indicators by agency and throughout the cooperative.

Implications for a case management research agenda

Careful analysis of our experience and the knowledge we have gained from it will help our partnership of agencies face and resolve these issues. Research into a number of aspects of case management could provide important assistance. Of particular interest is research regarding the impact of locus of practice (Piette, Fleishman, Mor, and Dill, 1990), organizational culture and practices (Sowell and Meadows, 1994, and the extent of formal and informal organizational inter-relationships on individual client outcomes and on the organization of a system of care. For case management-related research to be most useful, it should be multi-dimensional, practical, and self-supporting.

By multi-dimensional research, we refer to studies that incorporate the multiplicity of variables affecting case management outcomes. The research should examine questions related to the individual client and how what is done with the client, over what period of time, and by whom, affects client outcomes. Questions that examine the impact of agency-level variables, such as type, size, or organizational culture, and their impact on client outcomes must be addressed, as should questions related to variables within the HIV system of care, such as the level of cooperation among agencies (and whether cooperation is formal or informal), and questions related to the larger health and social services system in the community.

While seeking to understand the many dimensions of case management and the organizational, environmental, and individual factors that affect outcomes, researchers in this area also must be practical. If possible, the data gathered should be of immediate practice-related use. For example, data gathered for a research project could be immediately used as part of a client or family assessment for service planning or for organizational assessment to plan technical assistance programming. Each set of data on clients or organizations could then be aggregated for the larger research purposes.

Active involvement of front line agencies and staff early in the research design may lead to the development of approaches that are creative and serve multiple purposes. This collaborative approach can help develop relationships among the researchers and the front line agency that enhance joint ownership of the project and garner better results for both parties (Figert and Kuehnert, in press).

Finally, case management research efforts should be fully supported by research dollars. Too often, case management evaluation and research have relied on the goodwill, time, and, in some cases, considerable effort of agency staff, all without compensation. Truly self-supporting research should not

drain resources from practice efforts. Research efforts should either be adequately staffed for all aspects of the project or be able to fully compensate the agency for the costs incurred.

Conclusion

Those of us engaged in HIV case management using a collaborative, inter-agency model do so because we believe that such an approach leads to better client outcomes and a more efficient care system. We look forward to active participation in a rigorously designed and executed health services research program that fully examines the effectiveness of HIV case management. Such research will lead to improvements in case management practices and, ultimately, the quality of the lives of persons living with HIV.

References

- Figert, A. and Kuehnert, I? L. (In Press). Doing good while doing good science: AIDS/HIV services in the western suburbs. In P. Nyden, D. Burrows, A. Figert, and M.Shibley. The collaborative community: New models for social research. One Thousand Acres, California: Pine Forge Press
- Land, H. (Ed) (1992). AIDS: A complete guide to psychosocial interventions. Milwaukee: Family Service of America.
- Miner, B. (1995, September 10). Personal communication.
- Mor, V., Fleishman, J. A., Allen, S. M., and Piette, J. D. (1994). Networking AIDS services, Ann Arbor, Michigan: Health Administration Press.
- Piette, J., Fleishman, J. A., Mor, V., and Dill, A. (1990). A comparison of hospital and community case management programs for persons with AIDS. Medical Care,28(8),746 - 755.
- Ross, Murray G. (1967). Community organization: Theory, principles, and practice. (2nd ed.). New York: Harper and Row.
- Rothman, J. and Tropman, J. E. (1987). Models of community organization and macro practice perspectives: their mixing and phasing. In R. Cox, J.L. Erlich, J. Rothman, and J.E. Tropman (Eds.) Strategies of community organization (4th ed). Itasca, Illinois: F. E. Peacock, 3 - 26.
- Sigmond, R. M. (1995). Back to the future: Partnerships and coordination for community health. Frontiers of Health Services Administration.11(4), 5 - 36.

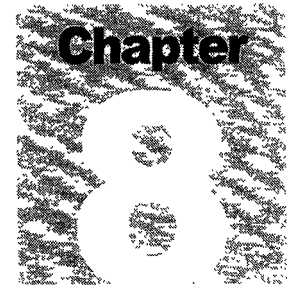
Sowell, R. L. (1995). Community-based HIV case management: Challenges and opportunities. Journal of the Association of Nurses in AIDS Care **6**(2), 33 - 40.

Sowell, R. L., and Meadows, T. M. (1994). An integrated case management model: Developing standards, evaluation, and outcome criteria. Nursing Administration Quarterly. **18**(2), 53 - 64.

White, W.L. (1994). Voices of survival, voices of service. Chicago: AIDS Foundation of Chicago.

Winkle, C. and Carr, A. (1995). Evaluation of the Ryan White CARE Act Title I as implemented in Chicago, Illinois. Chicago: unpublished.

Wolf, L. (1995, September 10). Personal communication.



HIV Case Management Compared to Other Models of Care Coordination

George *E.* Sonsel *LCSW**

Case management has become the primary method of coordinating care for people with HIV disease. The two primary sources for public funding HIV health and support services are Medicaid and the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Reimbursement of case management is allowed under the Medicaid waivers program. The various titles of the CARE Act range from mandating case management to strongly advising it be delivered as an option for coordination of early intervention services. These precedents were established through Federal and private foundation CARE Act predecessors. The AIDS Services Demonstration Program and the Pediatric AIDS Demonstration Program, both managed by the U.S. Health Resources and Health Administration (HRSA) expended significant resources for case management. The AIDS Health Services Program, sponsored by the Robert Wood Johnson Foundation, also relied heavily on case management as the primary resource for care coordination. It conducted some of the earliest studies on its practice in the HIV arena, delivery models, and impact on health outcomes and patient satisfaction.

But does this allow for the flexibility and adaptability required in dealing

*Mr. Sonsel, the director of mental health services for the Gay and Lesbian Center of Los Angeles, was formerly with the Special Projects of National Significance, Health Resources and Services Administration.

with HIV disease across these various domains? Are there special features about case management that make it particularly useful in coordinating care for those affected by HIV? The variations in definitions and flexibility in case management's practice, in fact, may be the very features that perpetuate its use over time, given the highly variable nature of the AIDS epidemic.

HIV disease remains a moving target from the perspectives of those populations affected by the disease, geographic location, progress in biomedical research, and socioeconomic impact. Yet for a service so widely supported and utilized under such diverse conditions, no single, universally applied definition of case management exists. Rather, case management is employed in different types of settings with population groups that display very different characteristics. It is practiced by both health and social science professionals as well as a variety of paraprofessionals.

The primary reasons for care coordination can be summarized by these four basic goals:

- . Achieve access to appropriate services in a timely manner;
- . Improve and stabilize health status and level of functioning;
- . Promote client participation in care decisions to better guarantee cooperation with health care recommendations as well as improve the quality of life as defined by the client; and
- Achieve delivery system efficiencies, including quality and costs of care.

Questions continue to mount about the effectiveness of case management as the primary method of coordinating HIV care. Evaluation of case management programs has offered some meaningful results. But these studies continue to primarily identify the inadequacy of measures for obtaining essential information on case management's effectiveness in coordinating care. These elements include:

- . Determining cost effectiveness;
- . Identifying what adaptations to its core elements can be made to accommodate special populations needs without compromising effectiveness;
- Assessing the impact of case management on health and other essential outcomes (such as social, psychological, spiritual); and
- Understanding the unique features of case management practice in the HIV service delivery system that set it aside as particularly useful for care coordination.

How case management relates to discharge planning services and the

integration of care in meeting the goals of case management is this paper's primary topic. Three methods of care coordination currently practiced with HIV population groups are examined: case management, integration of care, and discharge planning.

None of these models were developed exclusively for HIV care, but rather applied and adapted to meet the special epidemiological and psychosocial characteristics of the condition involved. The integration of care approach that appears in mental health services (when mental health services are integrated into primary care) was one of the first areas in which this concept was employed and studied in HIV care. Discharge planning, a fundamental service provided by medical social work and community nursing, matches resources with service needs.

Each discussion will include a description of the model, the organizational structures and cultures in which they typically operate, the populations served, adaptations required to meet population needs, and evaluation results (if available). Comparisons will be drawn across these approaches to care coordination to determine their similarities, differences, and barriers encountered in implementation and evaluation, and how implementation and evaluation can be organized to work together. The lessons that can be learned from the practice experiences of these methods will be discussed. In conclusion, a list of recommendations for further inquiry will be suggested.

A Case Management Paradigm

In 1993, HRSA's Bureau of Primary Health Care convened an invitational conference on case management for special populations. The purpose of the conference was to develop a common understanding of the content and structure of case management based on the experiences, expertise, and insights of front-line case managers, supervisors, program administrators, and evaluators funded through Title III (b) of the CARE Act. The result of the conference included a classification scheme that identified a core set of case management services as well as a set of supplementary services frequently provided by case managers in the Title III (b) program. This scheme is presented as a general point of comparison on the definition and activities of case management. The core services are listed as:

- Assessment;
- Care planning;
- Service arrangements and coordination; and
- Care monitoring and reassessment.

The conferees also identified the following supplementary case management services frequently required when working with special populations. These are listed as:

- . Outreach and intensive case identification;
- . Program eligibility assistance;
- Social and emotional support;
- System and resource advocacy;
- Patient/family education and training; and
- Provision of direct services such as specialized counseling or clinical care.

The Case Management Model

Case management is practiced in both hospitals and community-based organizations. There is also evidence to suggest that there are differences in structure and content of the services in these two basic environments (Piette et al., 1990). Case management practice in community-based organizations will be the focal point of discussion in this paper.

The three projects discussed here were supported by the Ryan White CARE Act's Special Projects of National Significance (SPNS) grant program for a period of 3 years. The National Native American AIDS Prevention Center focused on Native Americans residing in urban, rural, and tribal areas of Oklahoma. The Fortune Society served inmates and parolees in the City of New York and State of New York correctional systems. The Southeast Health Unit Summit on AIDS Care established wellness centers in 4 counties strategically located throughout a 16-county State Health District in Georgia.

Each program proposed goals for early identification and treatment of high-risk individuals, linkage with services based on a thorough needs assessment, follow-up on receipt of services, and client satisfaction. The National Native American AIDS Prevention Center and The Fortune Society are free-standing, non-profit organizations governed by boards of directors. The Georgia project is a coalition of providers from the health and social services departments of most of the 16 counties; the fiscal intermediary and administrator of the project was the Ware County Public Health Department.

National Native American AIDS Prevention **Center's** Ahalaya Project
Ahalaya is a Choctaw word meaning "to care for deeply." The project is a population-based model designed to provide culturally appropriate care to

Native Americans. The model is based on a profound respect for Indian spirituality and applicable use of traditional healing. It also embraces a health orientation approach that links western medicine and Native American cultural beliefs about disease and treatment. The project serves the client from entry into the project through death or as is determined by the client, such as self-termination or move from the area. Through letters of agreement with various institutions, clients are followed throughout the course of their illness and wherever that client is residing or receiving care. The program evaluation focused on identifying and tracking client demographics, matching service needs with appropriate providers and clients' satisfaction with the services, and outcomes of service provision.

The Fortune Society's Empowerment Through HIV Information, Community, and Services (ETHICS) Project

The ETHICS project places emphasis on client initiative and client-staff interaction to help clients access an array of needed services. The six-element model starts with outreach and HIV education in New York City prisons and jails. The correctional institution's culture obviously discourages self-empowerment and fosters dependency requiring the ETHICS model put a strong emphasis on self-initiative to support inmate and parolees efforts to overcome formidable social and psychological barriers to improve their health and socioeconomic status. Referrals to the ETHICS project most often are the result of frequent contact with ETHICS staff (self-referrals totaled 48 percent) and less from other prison sources. The project provides career development and training to clients to assist them to become self-supporting. Project staff are ex-prisoners, former substance abusers, or people living with HIV disease. Staff credentials, in the eyes of the clients, are based more on identification with the staff's ability to overcome barriers towards mastering their own lives than on educational status and professional licensing.

The Southeast Health Unit Summit on AIDS Care **Wellness** Centers Project

The Georgia rural network model was designed to deal with both the stigma and resulting social isolation of persons with HIV disease in a rural area. Limited resources (mainly due to distance between where clients reside and care sites), inadequate staffing in public health clinics, and poor funding for support services also were major considerations in the project's design. Two wellness centers (so named to avoid a connotation with illness) were established in community-based AIDS agencies, another in a multi-service public health center, and a fourth in the office of a private practitioner. Two substance abuse storefront treatment 'programs served as outreach sites as well.

All sites were staffed by a nurse practitioner, a social worker from the county social services department, and a mental health professional from the county mental health department. The community-based AIDS organizations provided support groups in each site. One site had a full-time case manager, while the other sites utilized one of the other three personnel as the designated case manager. The case manager conducted all the comprehensive assessments, developed a care plan, made and followed up on referrals, etc. Primary services were available on-site (primary care, mental health, enrollment for entitlements, and the support groups); the case manager was primarily responsible for outreach and arrangement of support services provided by agencies outside the wellness center. This often included arrangements for sub-specialty medical services and hospitalization in urban areas located 100-200 miles away from the health district.

The project planners severely underestimated the rate of growth in the caseload since nearly all of the previously known cases were gay men who had voluntarily tested for HIV. As a result of outreach at the substance abuse sites, African-American women who knew their sexual partners were IV drug users chose to get the HIV test and subsequently entered treatment. At the conclusion of the project, nearly 40 percent of the cases using the wellness centers were African-American women.

Evaluation results

Evaluations conducted by these three projects providing community-based HIV case management revealed that there were at least two essential elements of case management uniformly significant to retention and client satisfaction. These were:

- A major commitment of resources to outreach in order to initiate a personal relationship to overcome access barriers (such as geographical factors, cultural beliefs about mainstream health care, over-utilization of emergency care, and lack of knowledge about entitlements to pay for care as well as serving as a link to testing or treatment); and
- The integration of individual counseling or support groups by the case managers to reinforce positive behavioral responses to care (such as remaining in care, adherence to treatment regimens, practicing personal prevention strategies, making appropriate use of their natural support system, timely follow-up on referrals).

Client satisfaction was significantly linked to clients' perception of the quality of the relationship with their case managers, increase in knowledge

about the disease process, and the program ability to incorporate the cultural traits and values of the population it was serving. This supported a strong belief in employing people indigenous to the target population as case managers to expedite building a trusting relationship and engaging potential clients into the care system during outreach. This required an atypical amount of time and funds designated for training and other staff development activities.

A project's need for adaptability to frequent change in several areas was evident in both the narrative descriptions and data presented in the project's evaluation studies. Each project underestimated:

- The amount of start-up time and organizational resistance to incorporating innovation;
- The dramatic rate of growth in the caseload over brief periods of time;
- Fundamental capacity factors (e.g., staffing patterns, space, time required for data collection and entry);
- Evaluation costs;
- Resistance to acceptance of referrals by **traditional** providers;
- Need for provider education about HIV disease and the affected populations,
- Rapid change in the client mix from predominantly gay males to higher percentages of heterosexual substance abusers, women and their children, and persons with a dual diagnosis of mental illness and substance abuse; and
- The need for more field work to cultivate and train new referral resources.

It also required a multiplicity of roles for the case managers, a wide breadth of knowledge and skill, and at times presented serious personal conflicts and ethical dilemmas.

Integration of Care

Integration of care occurs between services at the intra- or **inter-**organizational level, as opposed to the practitioner-client level. Its purpose is to enhance coordination for the population being targeted for care. The study presented here discusses a series of projects representative of both intra- and inter-organizational integration of services.

The experiences of seven projects demonstrating integration of mental health services into HIV primary care settings were compared to determine if there

were any common features of their models that could predict positive health and client satisfaction outcomes. The study was conducted by the American Psychological Association for the Ryan White CARE Act's Special Projects of National Significance. The program identified continuity of care as a key indicator of services integration. The shared goal of the projects was to assure systematic access to mental health assessment and treatment as part of the primary health care regime for people with HIV disease. The most commonly used method for integration was to devise a system for delivering these services in a "one-stop shopping" model.

In five of the seven projects, mental health staff were stationed in primary care sites. Some of the projects experienced barriers to accessing clients in those instances in which a referral from the physician was required to initiate services. Most projects aimed to a case manager or mental health professional conduct the initial assessment of the patient's needs, including basic health care needs. Each project had anticipated the need for extensive up-front and ongoing training of primary care providers to assist them in developing a sensitivity and awareness of mental health and substance abuse problems and at what level they, as primary care providers, could be the first to intervene.

One project was designed to bring together three statewide systems of care on behalf of the HIV population throughout the State. These included the community mental health centers through their State association, the State-sponsored HIV care coordination agency, and private physicians with HIV patients in their care linked through a university medical school consultation line.

These projects primarily serve patients in outpatient settings; four sites are located at inner city hospitals. One project operated out of a university education department and another in a home health agency. The populations served tended to model the local HIV population in terms of risk factors. The primary source of reimbursement for medical care was Medicaid, with large groups of patients with no method of payment. One free-standing, urban, outpatient clinic had a patient population in which 71 percent received their care through a State uncompensated care program.

Results of the evaluation

The projects found that as mental health practitioners became progressively more involved with their clients, the clients expected and needed help managing other systems of care to find services such as food, transportation, long-term substance abuse treatment, housing, etc. Given the commitment to "one-stop shopping", staff had to develop proficiency in global

assessments, development of alliances with settings providing comprehensive case management, and active follow-up with clients. Several projects had initially built in a position of case manager that included a dual-role case manager and mental health provider.

The study concluded that project directors, for the most part, had interpreted HRSA's evaluation expectations as being more oriented towards monitoring project performance. This left a number of questions for future evaluation of systems level integration. Prominent among them is to what extent does the integration of service systems truly impact the need for a central coordinating service that assures global assessments, identification of resources outside the integrated system, and coordinated receipt of services internal and external to the system?

Discharge Planning

Discharge planning established its value primarily in acute care hospitals to ensure continued progress and stabilization of health status as well as prevent the recurrence of illness and untimely re-admission. With the introduction of the utilization review process by Medicare and Medicaid, discharge planning became an essential service, particularly in hospitals where major portions of patient populations were on Medicaid or Medicare. Indemnity insurers, self insurers, and health maintenance organizations also have subsequently recognized that close scrutiny of hospital stays and early engagement of discharge planning can significantly reduce the costs of in-patient care.

Discharge planning, as a method of care coordination, is primarily driven by the payor and institution's needs. The environment in which most discharge planning takes place requires that a high level of control be maintained by the provider. Responsiveness to the community it serves is important to the viability of an institution, such as a hospital. An issue such as personal choice, for instance, is not an essential element to the preservation of life. Essentially, for the time they are in the institution, patients are dependent on the providers to receive appropriate care. In the context of the institution's purpose, compliance is considered an appropriate patient response to ensure order and preservation of life. It could be expected that discharge planning also is carried out with these environmental requirements in mind. In fact, in a recent study of 36 non-profit, acute care hospitals, researchers found that patients participated at low levels in the discharge planning process study (Kudischin and Kulys, 1994). The authors concluded that social workers need to be aware of the individual variation in the desire for control among

hospitalized patients and that they are more powerful than patients in the discharge planning process.

Once the patient is discharged, the discharge planning process is complete. It is a time-limited service and any ongoing coordination of care outside the institution must be referred out to another agency.

Comparisons between the Models of Care Coordination

The three coordination of care methodologies presented in this paper are not mutually exclusive services. Rather, they often can be used in combination with each other to enhance the timely and appropriate delivery of services. Several of the important distinctions between them are discussed below primarily as a means of understanding their significance under certain circumstances and how best to use them in conjunction with each other.

Organizational structures

Most of the projects discussed here are set in outpatient settings, either free-standing or attached to an urban acute care facility. The primary exception here is discharge planning which, for the most part, is practiced in hospitals, chronic health care environments, and correctional facilities. Since the focus of discharge planning is an effective release from the system (unless there is a significant change in the mission of those institutions), discharge planning will always be limited in its scope. It serves primarily as an adjunctive service to an external case management program.

Cultural sensitivity and adaptability

HIV disease, up to this point in time, has primarily affected populations from definitive cultures whether they are based on socioeconomic status, race, ethnicity, drug use, and sexual orientation. There is some evidence that the basic elements of case management are more easily adapted to the cultural variances in which HIV is unfortunately most prevalent. Integration of services also appears to require sensitivity to cultural variances if many of the essential support services are to be recognized and utilized by the HIV-infected community.

Populations served

Case management and integration of services are typically designed to meet specific characteristics of the affected population. Case management has been used for decades in other disease-specific systems of care (such as care for mentally ill, frail elderly, and the developmentally disabled). While discharge

planning must be responsive to the needs of the individual and meet **disease-specific** requirements, it does not appear to be as population-specific given that its primary purpose is to serve the institution and the payors of care.

Adaptations required

In the case of discharge planning, adaptations may be required to address the needs presented by the disease as they affect the individual, organization, and **payor**. Case management for HIV must adapt to the current knowledge about the disease process and the cultural background of the populations affected by it. In the HIV case management projects described, these adaptations appeared to be essential for effective functioning. In designing an integrated system of care, adaptations need to be considered that affect not only the responsiveness of the affected population, but the organizations involved in structuring the system.

Evaluation outcomes and barriers to evaluation

The effectiveness of discharge planning in accomplishing timely discharges and in preventing premature re-admissions is well documented. The lack of adequate evaluation of case management as a tool for care coordination seriously impacts on the ability of health care delivery systems to advocate for its continued use. The concept of integration of services in designing systems of HIV care has yet to be extensively demonstrated and evaluated.

Recommendations

Knowledge and skill in the use of case management as a method of care coordination needs to be developed and advanced. This paper concludes with recommendations for future study.

- Continue to work towards building consensus on a definition of case management as it is applied in working with the HIV population through qualitative studies observing case management in practice and isolation of variables most likely to affect changes in the system's responsiveness to clients' needs that influence their adherence to treatment and improvement in their quality of life.
- Continue studies on the contingencies of outreach that show promise in getting high-risk individuals to test for HIV and seek treatment earlier in the disease process.
- Evaluate the development and implementation of integrated service delivery systems and the role of a centralized case management program

for global assessments of clients' needs and for tracking the client's movement in the system to ensure timely and appropriate access and utilization of services.

- Develop intermediate means of establishing costs of case management, particularly as it relates to efficient care coordination and comprehensive utilization of services.
- Further inquiry to determine the significance of cultural sensitivity in relation to timely engagement in the client-provider relationship, adherence to treatment plans (including social rehabilitation), and improvement in the quality of life.

If implemented, these efforts will lead to a better understanding of the differences and similarities between various models of care coordination and of how they can be applied to meet the needs of people with HIV disease.

References

Gallegher, Tracey and Page, JoAnne. "The ETHICS Project: Linking Ex-Prisoners With HIV/AIDS to Community Services," Progress and Challenges in Linking Incarcerated Individuals with HIV/AIDS to Community Services, Health Resources & Services Administration, Bureau of Health Resources Development, Office of Science and Epidemiology, June, **1995**

Barney, David, Duran, Betty E. S. and Rowell, Ron. Part I: Oklahoma, Comprehensive Care Demonstration Project for HIV-infected American Indians, Alaska Natives and Native Hawaiians. National Native American AIDS Prevention Center, April, 1995.

Sparks, Caroline H., Dudley, Susan D., Uman, Kari F., and Gentry, Jacquelyn H. Integrating Mental health Services and HIV/AIDS Primary Care, American Psychological Association, Office on AIDS, September, 1994.

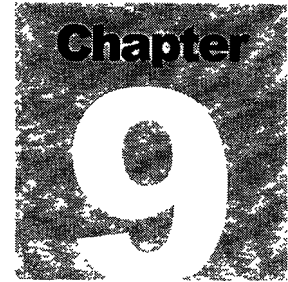
Piette, John, Fleishman, John A., Mor, Vincent and Dill, Ann. "A Comparison of Hospital and Community Case Management Programs for Persons with AIDS," Medical Care, August, 1990, Vol. 28, pp. 746-755.

Kadushin, Goldie and Kulys, Regina. "Patient and Family Involvement in Discharge Planning," Journal of Gerontological Social Work, 1994, Vol. 22,

pp. **171-199**.

Roberts, Cleora S., Severinsen, Cindy; Kuehn, Chuck; Straker, Drew.
“Obstacles to Effective Case Management with AIDS Patients: The
Clinician’s Perspective,” Social Work in Health Care, **1992**, Vol. **17**, pp. **27-**
40.

Proctor, Enola K., Morrow-Howell, Nancy, Lott, Cynthia L. “Classification
and Correlates of Ethical Dilemmas in Hospital Social Work,” Social Work,
1993, Vol 38, pp. **166-177**.



HIV Case Management for Special Populations: The Transition to Managed Care

*David P. Ley LCSW**

Case management is a well-established function of social service delivery. When a service provider discovers that someone he or she is caring for needs assistance beyond the provider's area of expertise, he or she becomes a case manager. The role of case worker and its attendant responsibilities became formalized in social casework and in public health nursing in order to respond to the social and health needs of the poor. Their aim was to maximize the effective use of public and charitable services, identify service shortages, and advocate for increased client assistance.

Today, case management is practiced to some degree by all service providers, by **payor** representatives, and by indigenous non-professionals in an effort to deal with the inefficiencies and service gaps in our health and social service system and its failures to effectively respond to certain populations.

In responding to this fragmented and inconsistent system, HIV case management experienced many changes. In recent years, the urgent **bio-psycho**social needs of people with HIV have challenged the current structure of health and social services. Given the trends towards specialization, medical care, mental health, and substance abuse treatment have become separated into parallel systems of care. HIV case management, then, helps people

* David P. Ley LCSW is the former director of psychosocial services at the Erie Family Health Center in Chicago, Illinois.

obtain complex services and overcome barriers in this “non-system.” This has proven a rich experience for members of affected communities and providers of health and psychosocial care alike in what is often an heroic response to meet the staggering needs of people with HIV.

Special Populations

People with HIV disease have been treated as a special population in the health care system and are often divided into sub-populations with distinct needs. These sub-populations include women, children, gay and bisexual white men, gay and bisexual men of color, substance abusers, adolescents, and hemophiliacs. Further consideration within this classification is given to members of poor, ethnic, and racial groups. Members of these latter sub-populations often face additional barriers in health care because of the fear and stigma associate with AIDS. Often homeless or marginally housed, socially dysfunctional, and presenting with chronic patterns of substance abuse and mental illness, these individuals are deflected from sources of care. Many clinicians view them as untreatable and they, in turn, have developed a complex mix of adherence issues through a long history of rejection and treatment failure.

The obvious intent of the classification of special populations is to bring attention and resources to their complex needs and to cut through their sense of alienation. Further emphasis results from the public health practices necessary to adequately screen, treat, and monitor infectious diseases. Special case management and treatment practices have been employed to reach these populations that often are vulnerable to infection. The employment of special and usually separate approaches reflects and perpetuates the deep divisions in our health care system and society. What special populations share in common is the limited reimbursement available for their overwhelming needs. (Their health care costs are sometimes addressed through public entitlements, which are always limited in the services they reimburse.) Case management, in-home services, and other needed components of care have been subsidized through special waivers and categorical funds. The result has created a financing infrastructure that is overly complex, unstable, and difficult to integrate into a comprehensive service delivery plan.

HIV and the recent reoccurrence of tuberculosis have demonstrated the need for a coordinated, comprehensive, and preventive response from our system. The further specialization of HIV and other infectious disease services -- poorly distributed and dependent on an inconsistent and highly politicized

system of categorical funding – has created financial and treatment issues that need to be addressed in the context of health care reform. The richness of the experience of HIV case management needs to be incorporated into a comprehensive health care delivery system that will respond to all patients without regard to their psychosocial or disease presentation. HIV care for special populations should be managed within the context of **community-**based, family-focused primary care and financed as an integral service under a **capitated** managed care system.

This paper will draw on the experiences of developing a case management system in Chicago that facilitated care across the city and region to “special populations” of injecting drug users, affected women and children, and gay and bisexual men of color. This experience was concentrated in a community consortium developed in a Federally funded community health center and involved the participation of indigenous personnel and community-based health, substance abuse, and mental health providers. Members of this group were involved in the formation of a regional case management cooperative, in city-wide outreach programs to injecting drug users, and gay and bisexual minority men, and in Chicago’s needle exchange program. These methods now are being applied to populations infected by tuberculosis. The paper will describe the roles and activities of indigenous personnel in case management and propose a model of integrated service delivery that incorporates case management into a community-based primary care system positioned for managed care.

Case **Management Within** Managed Care

Case management means different things to different people. An informal **typology** emerges according to the functions and objectives of those establishing case management systems. Raiff and Shore identified two paired dimensions of case management models. Models that were system-focused and clinically focused and models that were client-focused and ecologically focused. A third dimension has emerged that is payer-oriented and focused on cost efficiency issues. In some ways, these can be represented as three separate points on a continuum moving between a cost-efficiency focus on one side and, on the other side, a client-centered focus. A clinical focus falls somewhere in between. Different case management models find a place along this continuum.

<u><i>Cost-efficiency</i></u>	<u><i>Clinical</i></u>	<u><i>Ecological</i></u>
Payer-focused	System-focused	Client-focused

All models claim to encompass to some degree all of these concerns. However, the focus of intervention, scope of case management relationship with clients, and the roles played by case managers are generally dictated by the mission of the organization establishing the system.

Payer-focused case management models are designed to allocate scarce resources and reduce health care costs. Accomplishing this through rigorous monitoring of health care access, payer models portray case managers as monitors and evaluators of provider and client activities. The role of a therapeutic relationship in case management is de-emphasized, thus enabling case managers to service large numbers of clients in limited encounters. Clinical concerns and client needs are not of primary concern in decisions made under this model.

Clinically focused models are set by health and social service providers. Case management is focused on assessing and coordinating the use of varied services and on monitoring a client's response to treatment. Decisions are based in the clinical acumen of the provider and the objectives of the treatment system. These decisions must be reconciled with reimbursement and staff resource issues which often limit assessment and service of client needs. Clinically oriented models emphasize the traditional roles of assessment, care planning, and referral but limit their involvement to the fulfillment of their clinical purpose or agency mission.

Client-focused approaches set their priorities through a comprehensive assessment of client need and performance of a set of activities that promotes client service in home and community settings. Assessment and treatment of total client need is viewed as paramount. Reimbursement issues and service limitations, in an advocacy context, are viewed as barriers confronting clients living in an ecology of oppression and poverty. The importance of sustaining consistent relationships between client and case manager is primary; the traditional scope of monitoring and coordinating services is expanded to include direct interventions, such as counseling and advocacy. This is viewed as necessary to help clients navigate increasingly fragmented systems, mediate communication barriers with providers, and maintain consistent contact with clients whose access to services are delayed or infrequent. In summarizing these differences in emphasis and focus, one cannot escape noticing the tension that develops along all continuums.

Goal, Case Management Relationship, and Roles			
Element	Payer-focused	System-focused	Client-focused'
Goal	Resource allocation and cost reduction	Delivery of provider-determined care plan	Assessment and service of total client need
Case management relationship	Minimal	Limited	Primary
Role	Monitor access and evaluate provider activity	Assessment, care planning, and monitoring	Facilitate access and service delivery

For example, benefits assured through a client-focused model may sacrifice the efficiency sought by a payer-focused model. In a study of long-term care, case management was successful in facilitating access, coordinating care, and increasing client satisfaction. At the same time, however, it also increased utilization and did not yield expected cost reductions. An understanding and resolution of these tensions is important as health care financing is being reconfigured. A freshly conceived concept of case management that integrates these perspectives will be valuable in a managed care environment.

The present managed care scheme claims that the tension between payer-, provider-, and client- focused orientations can be successfully exploited to achieve all goals. In marketing terms, "managed care is quality care." Efficiently managed services will yield improved health outcomes, satisfied patients, and a happier health care workforce. Through negotiation of capitation rates, managed care shifts responsibility for service utilization to the provider. A standard reimbursement rate per patient creates incentives to efficiently manage utilization towards the least expensive services. Ambulatory primary care responses are maximized and, within primary care, services provided by non-physician, less expensive members of a team increase profitable service. Provision of nursing, social work, and other case management services will be determined by their utility in maximizing patient flow and assuring efficient provider practice.

Equally important in the theory of marketplace competition guiding managed care is the need for successful models that respond to consumers and are able to attract and maintain patient participation. Patients tend to respond and develop loyalty to systems that provide caring and consistent

relationships. In this atmosphere, as providers face increasing pressure to increase patient numbers and to screen cases to lower-level staff interventions, good case management practices, applied through a well-coordinated team structure, play a vital role in assuring patient satisfaction. The employment of community staff in roles that attract and maintain patient involvement could provide a competitive advantage and provide a cost-based rationale for indigenous case management.

Indigenous Case Manages

Indigenous community members have played an important role in the development of community-based primary care and HIV case management for special populations. Indigenous workers are members of the community or subculture whose attitudes, values, and behaviors are shared with both community members and providers. This commonality has been employed to foster positive relationships between members of class, ethnic, and racial groups and professionals practicing traditional allopathic medicine. They have been employed in many of the support positions in a health setting and their role has been vital in providing effective care. As case managers, their roles have varied from simple outreach and education to full partnership in treatment services.

HIV case management generally has emerged as a client-focused system providing services in home and community settings as well as in treatment institutions. HIV, in all but its end stages, requires intervention that is less medical and more psychosocial. Indigenous personnel have been effective in assisting professional providers in assuring case finding, follow-up, sustained engagement, and adherence to treatment. They also have assumed roles in mediating communication and overcoming barriers and in providing supportive relationships that help clients through periods of denied or delayed access and treatment resistance.

Many of these roles have evolved informally in response to the needs and problems the affected population encounter when seeking services. These roles and responsibilities need to be articulated in the context of the health care team. At a recent conference on managed care, the keynote address emphasized team coordination: "Teamwork is absolutely necessary. Put a value on each member of your staff. It's wasteful for any members to work at tasks that don't make full use of their capabilities." The model presented below attempts to incorporate the experience gained in HIV case management into an effective primary care team. It also poses case management as an essential

service in managed care and hopes to prove its effectiveness in achieving goals of efficiency and quality.

Experience in a Community **Consortium**

In 1988, Erie Family Health Center, a federally funded (330) community health center, formed the Integrated Care Consortium (ICC) with the Community Outreach Intervention Project and El Rincon Supportive Services, a methadone program. The Consortium was formed to provide integrated health and psychosocial care to HIV affected injecting drug users and their families and partners. The Consortium serves neighborhoods that are predominately Mexican and Puerto Rican and a population that is medically indigent, often homeless or marginally housed, and alienated from traditional sources of care. In its second year, the Consortium was funded as part of the Alcohol, Drug, and Mental Health Administration/Health Resources and Services Administration (HRSA) Linkage Initiative and continues as one of the 18 projects funded by the Substance Abuse and Mental Health Services Administration/HRSA Linkage Initiative. Over the years, it has expanded the scope of its services to include gay and bisexual men of color, women, and children.

The Consortium operates from an orientation of graduated and sustained engagement with its clients. The Consortium advocates harm reduction and stages of change theory. **With** this approach, clients are engaged at their level of readiness and helpful relationships are developed that may lead to further levels of treatment as need and readiness changes. The focus of engagement is reducing harm to self or others and helping clients identify behaviors that they are ready to change. To link services across agencies and to provide continuity of care to a highly mobile and difficult treatment population, the Consortium has developed a system of indigenous case management that has evolved into three levels of skill and role focus.

Level I: Outreach

Outreach workers provide the interface with the members of the community whose level of participation in treatment is minimal. This involves an ongoing presence and participation in the affected community and in street life. Their case management function is one of service linkage and follow-up. Outreach workers are the bridge between the community and treatment providers. They provide education and encouragement to both clients and professionals. They inform clients of ongoing behavioral risks, the presence of developing physical symptoms, and the advantages of care. They help professionals interpret client behavior that is confusing or hostile, question

provider responses that cause further alienation, and advocate for continuing efforts to reach difficult clients. They apply the initial principles of harm reduction and work with clients to slowly graduate their movement towards traditional care.

Level II: Family Case Management

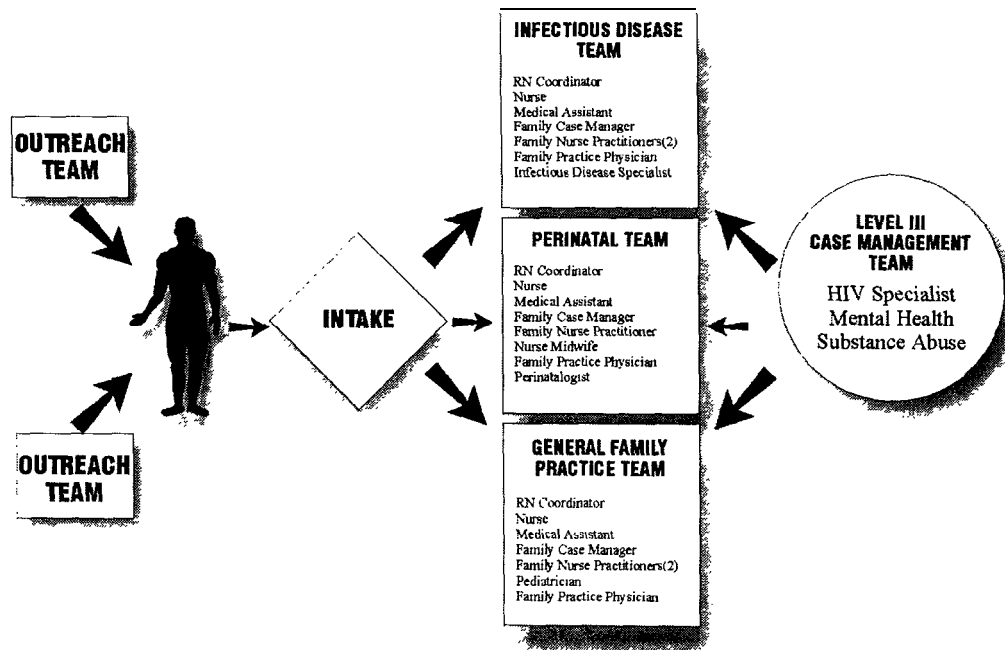
These roles also are performed by indigenous community members who serve at the interface between the target population and treatment agency. However, the performance of these roles is more firmly established in the agency office. At the core of the role of the indigenous community member are assessment, service planning, and facilitation of service delivery. Working in an integrated fashion with the treatment team, they rely on establishing a rapport with clients that supports treatment goals. The indigenous community workers collaborate closely with outreach staff, maintain consistent contact with families, and uncover client needs. They also develop strong referral relationships with staff in community agencies and are able to arrange and facilitate delivery of complex service plans. Management of data collection necessary for services, entitlements, and evaluation of patient care is another important role of the indigenous community member.

Level III: Specialized Case Management

At an advanced level of case complexity and need, case managers with more **highly developed skills** are needed to assure effective care. Established criteria including physical health and psychosocial complications determine the need for intervention at this level. Although nurses and social workers often perform these functions, the Consortium has employed indigenous members with baccalaureate degrees and significant psychosocial experience to successfully address the needs of complex cases. These case managers offer the community liaison capability of the other levels of case management, as well as advanced counseling and support of clients and management of complex cases.

These levels of case management are being incorporated into a model of multi-disciplinary team intervention applied to all families seeking care at the health center. The model applies the team assessment and service planning experience developed through the Consortium and other health center projects targeting special populations (The Health Moms/Health Kids, a Pregnant/ Postpartum Women and Infants project, Healthy Start, and a Family Intervention Project). Its implementation will restructure treatment and case management resources in an approach emphasizing the efficient utilization and quality assurance of managed care.

Multidisciplinary Clinical-Case Management Team Approach Model



The goals of the clinical/case management team model are to:

- maximize interdisciplinary communication and cooperation;
- streamline the process of patient visits;
- assess and respond to the comprehensive needs of families;
- determine the most efficient use of staff resources for each patient need;
- monitor and evaluate client utilization and staff performance;
- create a user-friendly patient environment through the establishment of a coordinated set of helpful relationships; and
- increase job satisfaction by creating an environment of cooperation and interdisciplinary mentoring and job development.

Clinical care is provided in teams coordinated by an experienced registered nurse. Clinic preparation, laboratory services, and treatments are provided by nurses assisted by medical assistants. Charts are reviewed 2 days in advance and all essential materials and information are prepared for the providers during set up. Streamlined-routing of the patient family visit is anticipated and assured. Care is provided by a three-level team of family

nurse practitioners, a family practice physician, and an infectious disease specialist. The family nurse practitioners provide services in outreach locations, and in the health center, working in close coordination with the physician providers. The provider composition of teams varies. For example, one team includes a pediatrician and a nurse midwife. An infectious disease specialist and a staff perinatologist are available to the teams for consultation and care of complex cases and may be integrated into a specific team.

Families are referred through the outreach teams working through specialized community agencies and through a registration and initial assessment process, coordinated at the health center, which is staffed by indigenous community personnel. Assessment is continued during measurement of vital signs and patient history-taking activities by nurses and medical assistants. A family case manager, who schedules return and referral appointments and reminds patients of up-coming visits, conducts further assessments. Information is collated in a computerized case management record and reviewed under the coordination of the team. The need for specialized case management is determined by established criteria and may involve the intervention of a registered nurse, nurse specialist, clinical social worker, or an indigenous case manager. Services include health education; home assessment and care; mental health and substance abuse counseling; referral and entitlement assistance; and individual, group, and family supportive counseling. Practitioners work across teams and assist provider and patient liaisons.

Teams meet regularly to assess cases and patient care practices. Data feedback on team encounter numbers, kinds of cases seen, return and failure rates, scheduling flow, staff activities, and patient utilization and referral are provided through a centralized information system and reviewed in team meetings. These data also are reviewed by health center administrative directors and program management to set and monitor performance goals. Patient satisfaction surveys are reviewed in customer service orientations during team and larger staff meetings. The establishment of helpful relationships and satisfaction of client need is emphasized. In establishing a successful team environment employing professionals and indigenous personnel, several areas of concern are worth noting.

Roles and Identities

In community agencies funded through a combination of revenue and categorical grants, the separation of staff activities and confusion of overlapping and integrated roles and responsibilities are inevitable. Added to

this are differences in professional identities and approaches to work. These often lead to an uncoordinated matrix of staff relationships or what is referred to in management jargon as “stove-piping.” “Stove-piping” refers to the operation of different programs, different departments, and different sides of a clinic by staff without a clear knowledge of the operations of other units of the same organization. Physicians, nurses, social workers, professionals, case managers, medical assistants, and support staff all have rarely articulated traditions with each other and among themselves as to their role and performance in a particular setting.

These issues are long standing and need to be approached sensitively and firmly to avoid confusion and identify areas of conflict. A careful and comprehensive survey of staff perception of operations should precede any attempt to reorganize. This survey should include sessions with all staff groups to allow them an opportunity to describe their present activities and the ways in which they envision positive changes in these activities in a team model. Clear job descriptions that include an expression of overlapping and team responsibilities should be well-articulated as an integral part of team organization.

The Erie Health Center experience has been gratifying with its almost universal consensus on the need for change and on the concept of an integrated team model. This supports the assumption that the team model is an expression of good clinical logic. However, another challenge is confronted during implementation, when new task functions and previously unasked for cooperation are expected. Areas of conflict and misunderstanding must be identified at team meetings and addressed from a perspective of common learning and education. The role of a nurse or other team member as a sensitive group facilitator is crucial in successfully building team cooperation.

Personality versus Principles

Evaluating the ability of individual staff members to function in a team environment requires performance evaluation. The problems of an individual in a team environment are sometimes the result of personality conflicts. However, it also may be the result of a poorly defined job description, poorly matched skills and function, or lack of support or a failure of response by other team members. If a principle or procedure in need of change can be identified and addressed, the situation can be improved through training, support, or a position change.

Manageable and Definable Objectives

Large goals are not operational objectives. Process must be aimed and attuned to identifiable and observable behaviors. Goals, such as streamlining patient visits or maximizing communication, are too broad and vague. Examples of measurable objectives are: reducing the number of patient visits, keeping the maximum number of rooms filled per clinic session, reducing the number of patients who do not appear for scheduled appointments, and anticipating patients who do not appear for scheduled appointments and filling their appointment slots with other patients. These objectives should be tied to ongoing feedback from the information system.

Facility and Equipment Support

Teams need team staging areas, where team members can informally gather, chart, review, and confer during clinic sessions. Any structural or equipment assistance, carts for charts, small openings in the walls between rooms, counter tops, computer monitors for appointments, easy access to treatment rooms, scales, and laboratory equipment help create a team environment.

Meeting time

To assure efficient productivity, it is essential to allot ample time for team meetings and clinical training. Administration must support meetings and training and realize that efficient functioning will not appear immediately, but will develop over time. The initial phase of teaming may be time-consuming and raise issues that require resolution.

Ongoing Job Development and Training

A goal of the team model is to create an environment that develops the skills and level of participation of all team members. The need for ongoing training – from on-the job procedural “check-outs” to formal presentations and lectures – is important to all levels of staff.

Ongoing Evaluation, Feedback, and Incentives

This model is fueled by an assumption, based on experience, that an integrated clinical and case management team will be able to increase patient flow, maximize staff productivity, and, as a result, increase reimbursement revenue. Increased revenue will eventually enable health centers to finance case management services without dependence on categorical funds. The model also assumes that indigenous workers perform an important role in providing continuity of care. Such assumptions need to be verified through effective evaluation. Progress toward the desired goal requires careful monitoring that is supported with ongoing feedback provided to the teams on productivity, revenue, and patient satisfaction. In addition, performance data should be tied to staff salary and bonus incentives.

Agencies funding public health care should expect a period of transition. Research and service dollars funding special populations should be spent in evaluating models that integrate case management services in managed primary care. Evaluation should identify specific case management services needed by each special population as well as the effect these services have on negotiated capitation rates. In the likely event that continued subsidy is needed to support case management and other services for members of special populations and residents of indigent areas, that subsidy should be applied as an increment in the **capitation** rate negotiated for these individuals.

Conclusion

This paper presents a model of multidisciplinary clinical and case management teams. The model integrates existing HIV case management resources for special populations into the operations of a community health center's primary care program. This model will position the center for managed care and formally articulate the roles and responsibilities of indigenous case managers in established health care positions. The model expects to maximize patient revenue and fund case management positions through the capitation scheme proposed under managed care.

The importance of this effort is emphasized by the following points:

- . HIV case management for special populations has been funded through unstable and highly politicized funding streams. It is time for these services to be rationalized under the current scheme of health care financing.
- . Indigenous community members have played a vital role in community health care. It is time that the roles and responsibilities performed by these individuals are clearly articulated in health care. This includes a differentiation of skill level, a graduated career ladder, and support for advancement. If the profession fails to do this, it will only offer jobs at the skill and compensation levels of household domestics.

If not approached within the context of health care reform, reform will abandon the role of community job development played by health centers and fail to employ those indigenous individuals whose participation has been crucial in making community health care a reality.

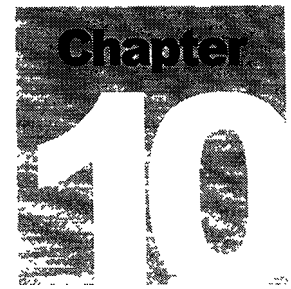
References

- Austin, C.D. Case management in long-term care: options and opportunities. *Health and Social Work* 8:1, 1983.
- Baker, Steven R. Conference remarks: practitioner skills for managed care. Northwestern Healthcare, Evanston, 1995.
- Crystal, S., Merzel, C., and Kurland, C. Home care of HIV illness. *Family and Community Health* 13, no. 2, 1990.
- Benjamin, A.E., Lee, P.R., and Sokowitz, S.N. Providing case management to persons with AIDS in San Francisco: trends and issues. University of California, San Francisco, CA, 1988.
- Falik, Marilyn. Case management for special populations: practitioner perspectives and recommendations. Health Resources and Services Administration, Bureau of Primary Health Care, Division of Special Populations, February 1993.
- Giblin, Paul. Effective utilization and evaluation of indigenous health care workers. *Public Health Reports*, July-August, 1989.
- Kemper, P. Case management agency systems of administering long-term care: evidence from the channeling demonstration. *The Gerontologist* 30, no. 6, 1990: 817-824.
- Koska, M.T. Case management: doing the right thing for the wrong reasons? *Hospitals*: May 1990.
- Piette, J., Fleishman, J., Mor V., and Dill, A. A comparison of hospital and community case management programs for persons with AIDS. *Medical Care* 28 no.8, August 1990.
- Raiff, N. and Shore, B. Advanced case management: new strategies for the nineties. Sage Publications, Newbury Park, CA, 1993.
- Sierra Health Foundation: Report of the national symposium on case management and HIV/AIDS. Challenges for the future: coordinating HIV/AIDS care and services in the next decade. December, 1991.

Weissman, Gloria. Creating an agenda for research and evaluation: HIV service delivery, the Ryan White CARE Act and beyond. Health Resources and Services Administration, November **1992**.

White, William. Voices of survival, voices of service: AIDS case management in Chicago. AIDS Foundation of Chicago, **1994**.

Willenbring, M., et al.. Application of case management in alcohol and drug dependence: matching techniques and populations. National Institute on Alcohol Abuse and Alcoholism, 1990.



HIV Case Managers: the Challenge and the Responsibility

*Ennes Littrell ACSW**

Although the term, case management dates back at least two decades, case management as a tool in providing care – particularly to the chronically ill – and as a profession exploded dramatically in the last 10 years. Several simultaneous factors contributed to the growth of case management: de-institutionalization of the mentally ill; the trend toward keeping families together rather than removing abused and neglected children from the home, the growth of managed care and cost containment in health care; and the emergence and persistence of the AIDS epidemic.

Case management now appears in a variety of settings, is performed by various professionals and paraprofessionals, and is delivered through various models. In some settings, case management may refer to a cost control, gate-keeping mechanism. Case management may also refer to information and referral services provided by advocates and dispensed outside a traditional helping relationship. Apart from the insurance industry, case management generally refers to a set of tasks agreed upon by the client¹ and case manager

* Ennes Littrell ACSW is former Executive Director of ActionAIDS, Inc., in Philadelphia, PA.

¹ For simplicity, “client” and “consumer” are used interchangeably in this paper. Both refer to individuals living with HIV, intimate care givers, families, foster parents, etc. Although people living with HIV are case managers, they are included with no special distinction when referring to case managers. HIV-positive case managers need the same supports and structures as other case managers. Their expertise in one critical area does not mean the same expertise or ability in all others dimensions.

to be carried out by following a plan that from time to time is reassessed.

This model of case management depends on the development of a relationship of trust between case manager and consumer. This model now is predominant in the HIV care system. For it to be successful, however, case managers must possess a set of skills and a set of attributes.

While models of case management and professional standards exist, little in the literature refers to case management personnel education, training, or standards. This paper attempts to contribute to this missing gap by combining the experiences at one large-city AIDS service organization (now 7 years old) with literature and models, along with the contributions of many individuals actually involved in case management.

Tasks of Case Management

Before exploring the issue of education, training, and standards for case management provision, the tasks involved in case management must be clearly defined and understood. From that understanding flow particular education and training issues and from these issues flow standards for individual case managers and for the organizations that support them. Proceeding in this direction allows us to see case management with a focus on the education, training, and professional backgrounds that case managers need in order to be participants in this method of service provision. Case managers cannot be separated from the process of case management any more than architects can be separated from design or accountants from mathematics.

What makes the “best” case managers? The best for whom? How do we evaluate effectiveness? Which person will be successful in responding to the demands and expectations of this particular job? After all, our expectations for case managers may be as varied as:

- having the ability to establish helpful relationships with an exceptionally diverse population;
- understanding a complex disease syndrome and its multiple, changing, complex treatments;
- knowing resources, brokering services, asserting and advocating for **their** client’s interest;
- empowering the client while being sensitive to the vicissitudes of HIV and its changing impact on the capacity for independence; and
- withstanding the anger and grief – theirs and the client’s – that accompany the disease.

For this set of extraordinary expectations, we traditionally compensate minimally. Do we also offer minimum preparation, support, and structure?

In what follows, the facets (both tasks and the relationship in which these tasks are identified and accomplished) of case management are explored. The education, training, and other supports necessary to accomplish the goal of quality case management for people living with HIV also are examined.

In approaching this issue, interviews were conducted with case managers representing a continuum of experience, with supervisors and agency managers, and with consumers of case **management**.² Educational and training needs were the focus of these open-ended, unstructured conversations. These conversations were in no way structured interviews and conclusions drawn entirely from them would be of limited value. This information, however, is supported by material from a regional case management/consumer **conference**³ and from more formal studies. Defining or establishing a framework to help ensure quality case management for everyone is indeed daunting. For care providers, however, this is the only acceptable goal. How we get to this goal will require the inherent creativity and flexibility of case management itself.

Types of case **manager/client** relationships

The following model demonstrates the various types or classifications of a case manager/client relationship. This model is proposed as being nearly universal, in that it demonstrates the life and movement of the connection between case manager and client by defining the mutual stake or investment in the interactive field.⁴ The figure below represents four types of relationships:

- A – the relationship between client and case manager in an information and referral type of case management.

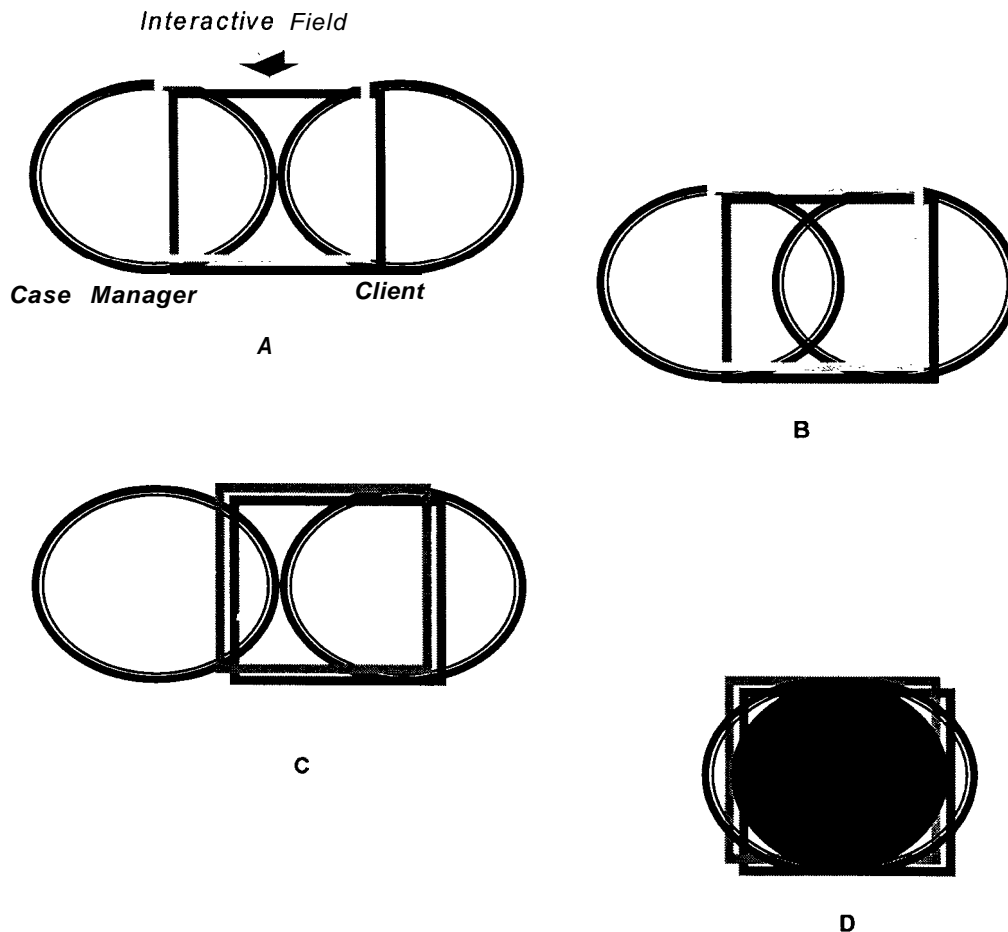
² Interviews were conducted with 23 consumers of HIV services, 15 case managers, and with the managers and supervisors of case managers in three different settings.

³ Common Ground. Moving Ahead: Designing Case Management System Coordination for our Region. March 28, 1995, Philadelphia, PA.

⁴ No mention is made in this paper of the issue of boundaries and limits. The model [Figure 1], by definition, deals with the changing nature of the client/case manager relationship. Experienced supervision becomes critical as it assists in evaluating the appropriate level of overlap that helps prevent the under- or over-involvement of a case manager.

- B – a more interactive model of case management at the beginning of the relationship when the typical investment of both parties is mutual.
- C – when little interaction is needed or required by the consumer and the case manager is pursuing and investing more in the interaction. This could indicate a beginning relationship, working to keep someone connected to care who by virtue of a disabling condition may not be able to invest in the interaction, or may not be motivated to continue.
- D – indicates a great deal of involvement or over-involvement of the case manager and client. This could be the end stage of the illness when client, family, and consumer are intensely connected or it could be an inappropriate over-involvement in the client's life.

INTERACTIVE MODEL



Description of case management

The tasks and processes of case management within the four types of relationships can be described in general as:

- assessment of all health and service needs;
- development of a prioritized intervention plan that responds to all identified needs;
- implementation of that plan through resource identification and linkage with requisite services;
- monitoring service delivery, adhering to plan, providing follow-along, supporting, advocating;
- reassessment and replanning; and
- evaluation of outcomes.

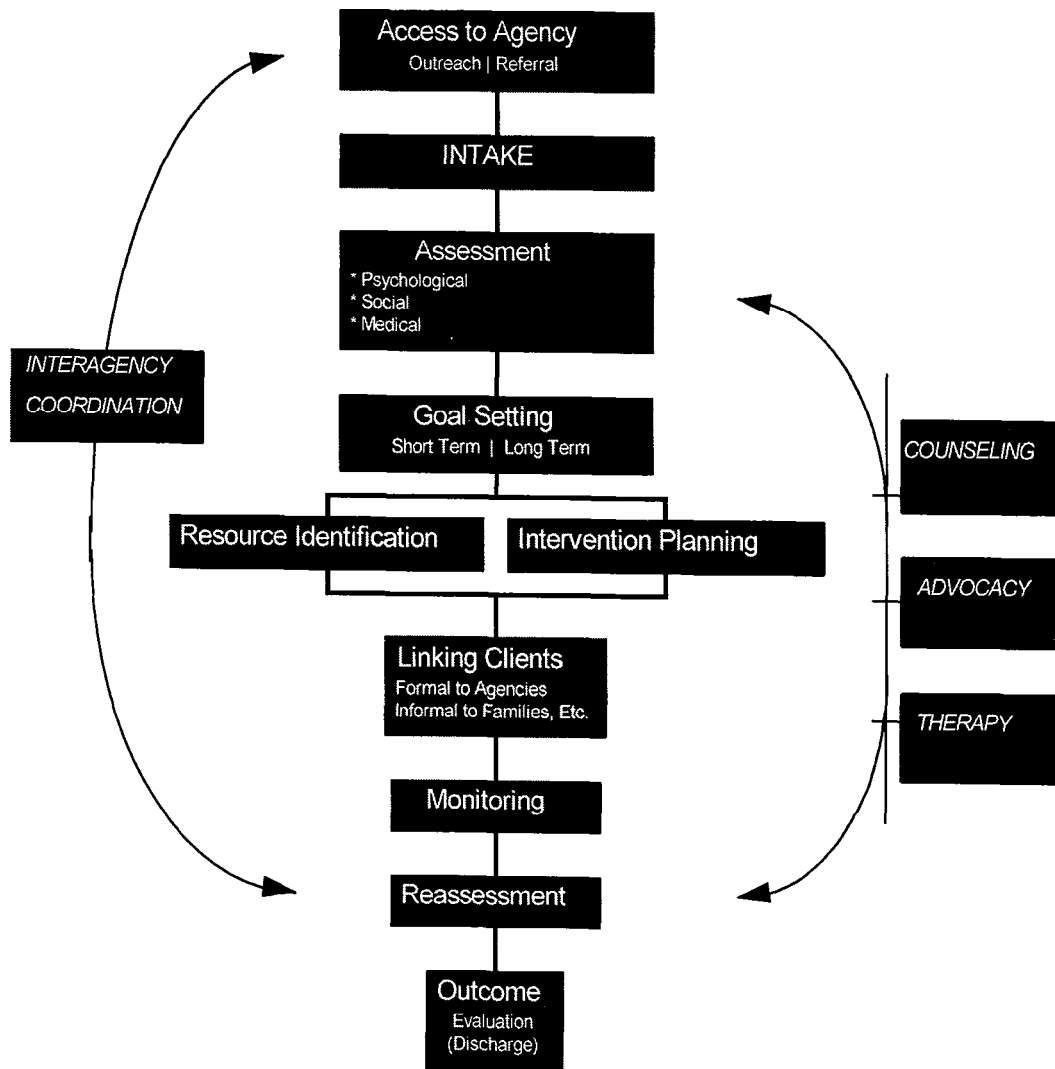
The figure below illustrates the flow of these tasks.

Recordkeeping is implied but not explicit in this description and illustration. This important task allows a consumer's "story" (protected by laws and rules regarding confidentiality) and therefore that consumer's resources, needs, and plans to be available from one case manager to another (through staff absences, attrition, and transfers) without requiring the consumer to retell the completed parts of the process. Keeping records is a form of communication, as important as any other in the continuity of care.

Attributes and **skills** of the case manager and **client**

No illustration can demonstrate the dynamism that is a necessary component of case management. This dynamism – much of which is a function of the relationship between the case manager and consumer -- requires of the case manager a special set of interpersonal attributes and skills. The vitality, this necessary energy, provides the drama and struggle of case management.

Case Management Model
(Figure 2)



The following factors move the case managers and consumers through the processes and tasks of case management:

- . flexibility
- . time
- change
- . pressure
- . disappointment
- success
- courage
- perseverance
- intelligence ⁵
- organization
- physical space

Even in systems in which case management is defined only as information and referral and may occur primarily through telephone contact, case management means working and communicating person-to-person or **person-to-people**. Case management has very little to do with managing cases or even managing others. It does have a great deal to do with managing oneself (both as case manager and client) and, in order to be successful, depends entirely on relating constructively to others.

Who needs HIV **case** management?

The easy response to the question “Who needs HIV case management?” is this: anyone living with or affected by HIV who wants it. This is the consumer response. Consumers interviewed also indicated that when they simply wanted information and referral, they did not want to be subjected to a process that went beyond their own definition of need. In general, consumers believed that case management became critical when they began

⁵ Includes “street smarts and savvy” as well as other forms of intelligence

seeking entitlements, concrete supports like housing, assistance with special programs (drug treatment, for example), and when they became ill. Both consumers and case managers, however, agreed that once a relationship develops, requests for less concrete needs (assistance in dealing with and thinking through diagnosis disclosure, spiritual needs, and support for dealing with feelings associated with HIV, for example) begin to be expressed.

As suggested below, education, training, and supervision permit case managers and consumers to be successful in reaching the goals of the case management plan. Some learning can be achieved didactically by merely presenting information in palatable, understandable ways. Some learning requires more effort. It requires more willingness from case managers to grow and more commitment from organizations to support that growth.

Matching clients with case management services

Case management is critical for those who are ill, even for those who have personal resources and may require little public support. For individuals and families who are disenfranchised (most often racial and ethnic minorities and women), case management following diagnosis is important, no matter what the degree of symptoms or severity of illness, at least until supports and service needs are evaluated, located, or if necessary, created, and are in place.

One way to assess the need for case manager use is to examine two variables: (1) consumer desire, and (2) the ratio between resources/current health status and resources/services/health care necessary to improve or maintain an acceptable quality of life. Necessary resources may refer to non-existent resources or to resources that exist but are not accessible for a variety of reasons (such as lack of transportation or prejudice). On the possibly quite long continuum between diagnosis and sustained illness, are case managers always needed? Are the case management skills needed along the way always the same? Appendix I describes an acuity triaging system (developed by ActionAIDS, Inc. in Philadelphia) for matching clients with the appropriate level of case management services.

Referring back to the above ratio (between what a consumer has and what is needed), a mechanism for assessing acuity or severity of life stresses and health status, we can imagine that one individual case manager may not possess all the tools necessary to provide service all along the HIV continuum. On the other hand, another case manager might be quite able to respond to the continuum, but not for everyone on it. That is, his or her

skills may be best suited for working with clients with mental health or substance abuse issues, with a particular racial or sexual orientation, or a certain ethnic group.

No matter how lofty, our values are regarding the capacity to work with everyone, allowing case managers to work within their strengths (while working to extend or deepen them) provides a number of critical benefits. A case manager who recognizes the value of his or her strengths and believes that others value these strengths is much more likely to successfully complete the necessary stretch and work involved in developing additional strengths.

Allowing this selectivity to the extent possible (and understanding the reality of waiting lists and urgent need), works best for the client/family when a team of case managers exists. A group of case managers meeting, working, consulting, and collaborating with each other provides a strength lacking in projects or programs with isolated case managers. In every team, however, consumers need a point person or primary case manager with whom to connect. This case manager is fed by the team, the team covers his or her emergencies, and knows the whole team's cases well. Joint visits are made to clients' homes. Team members are not strangers to the clients. (See below for more discussion of case management teams.)

Case managers: **born** or made?

In conversations with case managers and consumers, the following question was posed: "What fundamental skills should every case manager have?" The first answer in **90** percent of the responses was "listening skills." This response was mentioned in the top three by all but one person. Mentioned frequently by consumers and often by case managers was "understanding of the disease, its treatments, frequent symptoms, etc." Training case managers to integrate information about HIV into their repertoire of information clearly can be accomplished but requires frequent updates and repetition. The medical and related health complexities of HIV can be overwhelming (to both case managers and consumers), especially to those without a medical background. Nurse case managers on the HIV case management team increase the likelihood that a consumer's health will be monitored and understood and, therefore, responded to by all case managers, including the non-nurses. This model also provides a source of clinical interpretation or translation for consumers.

Consumers also felt strongly that case managers should be well versed in community resources and in how to make these resources available. Many

consumers indicated disappointment or irritation when they possessed information about resources that a case manager did not have. Consumers do not view it as their job to teach case managers. Perhaps this bitterness would dissipate if the model were able or allowed to be more collaborative. This expectation that a client should not need to educate the case manager may be unrealistic, given the ever-changing landscape of resources. The consumer's point of view may be that unless the case management relationship is really a negotiable relationship, a power imbalance exists. With this imbalance come, inevitably, negative feelings and competition. As a result, a typical consumer reaction is "I could do your job better than you do."

Case managers, as well as consumers, take very seriously their need to keep updated about resources and generally work hard to stay in touch with changes. They work hard at networking with other case managers and with other sources of information and they attempt to create effective mechanisms for sharing information.

Several case managers specifically mentioned the need for training in how to broker resources. Being aware of the resources is but the first step. Gaining access to them may require persistence, negotiation, and forceful advocacy. These skills, which go beyond networking and asking, are not normal parts of professional curriculum and for many case managers are not part of the skills they bring with them to the job.

Teaching case managers and consumers to listen, however, may be even more challenging. In discussions about what was meant by listening, both case managers and consumers talked of "hearing a client, really *understanding them and their world*, their issues and their needs; appreciation for the context of their lives." "Being heard" was defined as necessary to the development of trust; trust was fundamental for most persons living with HIV to frankly discuss their needs.

Can we train or educate case managers to listen? We know from experience that listening is easier for some people than for others. Individuals who choose to be case managers probably are more inclined than a general population to be good listeners. Discussions with case managers illuminated how highly they valued listening as a skill and how important and fundamental a skill they believed it to be. Many case managers believed strongly that education, in particular their education, was important in their own capacity to learn this skill. Most have backgrounds in nursing, social work (bachelor degree and master degree level), or counseling. All case

managers felt that supportive, skilled supervision had assisted them in developing their skills, or would assist them beyond their formal education.

Consumers were quick to point out that they were acutely sensitive to responding to another person's agenda. As we know, the HIV world is replete with strongly held views, assumptions, and stereotypes. Case managers generally come from a pool of people strongly committed to action and particularly action in the face of the HIV epidemic. Even though case managers are similar to consumer activists in their passionate commitment, they seemed eager to avoid putting anyone in "boxes," either themselves, their co-workers, or others.

Many consumers believed that formal, professional education is not an important variable in developing necessary skills for successful case management. They quickly pointed to individuals they knew who they believed performed case management responsibilities as well as or better than trained professionals.

Because case managers exist in a position of power in the case manager/consumer relationship, they have special responsibilities to be sensitive about how that power is perceived and experienced by receivers of service. As are many helpers, however, case managers are not used to seeing themselves as occupying the power position and may, therefore, unintentionally be insensitive or even abusive in the exercise of their responsibilities. Consumers cited insensitive questions regarding money management as an example of this case manager offense. Consumers also agreed that once they had been forced to justify a facet of their life to someone unfamiliar with their experience, asking for help with anything else became harder. Many felt unable to let the case manager know when they were offended for fear they would jeopardize fulfillment of future needs for service. That this power imbalance exists is likely to create specific tensions; case managers frequently are in a position to have or are perceived to have information and resources that clients want and may desperately need. It is possible – and perhaps possible to test – that consumers' tendencies to trivialize formal education come from this power imbalance. Lack of a professional degree actually may serve as an equalizer. Whatever the power issues, a key question remains: How do case managers get needed information from clients without offending them?

Role-playing was mentioned as a mechanism for training that case managers found helpful or would find helpful. Consumers felt training about listening that involved consumers was important. Role playing involving role reversal

was suggested as an example of consumer-involved training that consumers felt would support and legitimize their issues and concerns.

Consumers also felt it important that they have a role in hiring new case managers. They believe that their sensitivities would allow them to identify those who were not suited for the job and those suited for the job but in need of basic training. This perhaps unusual use of clients seems appropriate in that it lends substance to their involvement in the mutuality of the case manager/client relationship that is part of the case management jargon.⁶

Case manager: “If I’m African American and you are too, can I hear you better?”

Client: “No, but I might like the way you look better. And I might perceive that I am being heard better. And the power imbalance between us may not be as much of a barrier.”

Listening and hearing per se do not depend on race or culture except as language difference becomes a barrier. Because of the complexity of HIV and because of the fragmentation of our health and social service systems, case managers and clients must speak the same language. An effective case manager also must be culturally sensitive,⁷ even if speaking the same language, since speaking the same language in no way ensures cultural sensitivity. A case manager’s recognition that difference in race or culture may be a barrier in and of itself is the first step in developing cultural competence. Education about norms and values, awareness of baseless assumptions, and exploration and acknowledgment of bias and prejudice are necessary steps. Same-race, same-culture case managers will have their own assumptions to deal with. All of us tend, when we identify someone as “like

⁶ Perhaps originating in the mental health field, this use of the word “mutual” may create misunderstanding or unrealistic expectations. In many instances, for many legitimate reasons, the mutual development of a plan occurs long after the case management process begins. As one case manager explained, there are many clients who need a great deal of support before they can accept that they deserve to have a plan.

⁷ Cultural sensitivity can be defined as being aware of and in control of “isms” or working toward that goal, and extensive experience in working or living within the culture specified. This includes racial, ethnic, sexual minority communities, and other special populations such as the deaf community when referring to “cultures” in this context.

us,” to clothe them in ill-fitting stereotypes. Whatever blocks a case manager from hearing and understanding a consumer must be identified and removed. Training can help accomplish this, as can sensitivity workshops, as can experience. Experienced, competent supervision, however, may be the most powerful tool in achieving this goal.

Supervision is consistent over time and can reinforce growth and change. The impact of supervision can be increased if it occurs in a workplace where a diversity of professional background, cultural background, and particular skills exist.

HIV, mental health, and other needs

Many clients receiving support in case management programs are multiply disabled and multiply diagnosed. They may have several debilitating physical conditions. They may also have substance addiction or abuse issues and mental, developmental, or emotional disabilities. Such clients may be restricted in their capacity to engage in the case management process. Individuals with mental illness interviewed for this paper emphasized the importance of the consumer role in these instances. Their voices may be difficult to hear but they share the same need for dignity and engagement with trained and sensitive case managers. Again, specific training for work with these populations is critical for an effective case management program. Should individuals be case managed in an HIV program when these other illnesses or conditions, many pre-existing, are present? Again, this question can best be answered by the consumers. The primary source of their case management should be located where they are most comfortable. All systems involved with an individual or family must then cooperate in providing the necessary service.

Coping with problematic **situations**

Case managers feel they need to be equipped with skills -- which few feel they have -- to assist them in de-escalating problematic, dangerous situations. Crisis intervention skills are an important part of listening/hearing training. As important as these skills is the ability to anticipate the need to develop plans for responding to problem situations in ways that provide protection for the case manager, client, and others. Since case management is an activity occurring in homes, hospitals, long-term care facilities, shelters, prisons, clinics, and on the street, developing these plans can be complex. However crisis intervention or mediation is done, it must be and feel safe for both case managers and clients if it is to be effective.

Is case management a team activity?

HIV case management is a complex activity. In many communities, the luxury of bringing together case managers in one setting exists. In others, it will be impossible to bring together case managers from various settings who share responsibility for providing care to consumers. In some parts of the country, HIV case managers are quite isolated. Where teams -- particularly multi-disciplinary teams of case managers with different skills and backgrounds can be created and brought together -- the case management provided will be most effective. Given the current telecommunication possibilities, even geographically isolated HIV case managers work in environments where collaborative, team-like education and training opportunities are possible.

Wherever an HIV case manager and client are located, however, a project or program or funder or site has the responsibility of assuring adequate supports. Poor case management is dangerous; it affects entitlements, health care, and quality of life. While keeping case managers from operating in isolation may be a challenge, creating a team-like environment for case management is an important, if not essential, goal.

Death, dying, and grief

In discussions with case managers and consumers, only one person mentioned death or dying. In a recent case manager/consumer conference held in Philadelphia for regional case managers and people living with HIV, however, workshops offering support for grief and loss were packed to capacity. In discussions and role-play at that same conference, much of the focus was on death. "I cannot stand to lose another friend," "I'm fearful of dying and don't know what to say," "I don't know how to take care of myself or my clients when dealing with this issue," were all comments recorded that day. Organizations must push through the denial and resistance to the issue of death and provide outlets for grief and training on grief resolution as well as specific training about death, values, and cultural differences. Supervision becomes a private space for respite and support if supervisors are both trained and sensitive.

An integrated model of case management

Let us now return to the original model and add the dimensions of training, education, and supervision along with the resources, strengths, and needs of the consumer.

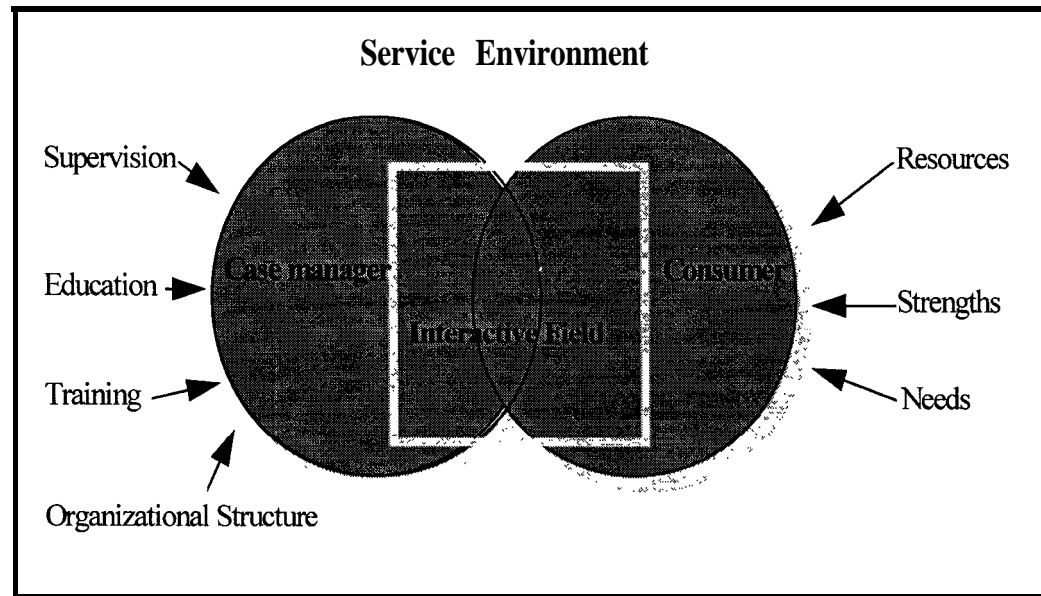


Figure 3)

This model highlights the background or the environment that needs to be in place surrounding the interaction between consumer and case manager. Effective case management requires an active, engaging background that supports and trains case managers, assists in creatively thinking about the challenges and struggles they face, and understands the tensions existing in the case manager/consumer relationship. This service environment occurs in the larger context of the client's life and place. This dynamic context of things like family, friends, location, and values feed the client's resources, strengths, and needs. Understanding this context is the essence of sensitivity.

Standards and evaluation

In examining the components and challenges of case management, we discover that defining a set of standards to measure a case manager's proficiency seems simple.

Case manager capabilities

A case manager should:

- . know and be able to access and broker resources;
- have a working understanding of HIV disease and associated medical issues;
- be able to listen;
- **be culturally sensitive for the targeted culture, if any;**

- . keep records of client-related activity;
- . be a problem solver;
- be able to integrate information from various sources; and
- be able to relate constructively to others

Structures of case management settings

Organizations, agencies, and settings for case managers should be committed to providing a set of important structures that include:

- . on-going experienced supervision;
- on-going training and education;
- . specific support especially for dealing with issues of grief and loss; and
- . periodically updated assessment tools.

Performance standards

In addition to activities in support of these structures, organizations or case management sites should have in place mechanisms for the measurement of five standards.

- standards of quality;
- expectations about maximum number of clients;
- secure work space;
- employee grievance procedure;
- . client complaint process; and
- . employee performance appraisal process.

Evaluation

With standards in place, evaluation can occur. There minimally are two levels of evaluation. First, we need to know how well case managers fit the job. How are they doing? Performance appraisal provides an occasion for self-assessment as well as supervisory assessment. (This assumes that organizations are first clear about these assessments as they relate to case management.)

Next, we need to know how the organization stands regarding its goals and mission. Is help being provided? Is it provided equitably? Are all the supports for case management in place that need to be in place? Measuring these principles generally means turning outside of the organization to funders, peer evaluation processes, and, most importantly, to those who use the services (both other care providers and consumers). Surveys, focus groups, and random sampling of clinical charts (to measure how and if resources are used and client contact information, for example) provide three possible tools for organizational feedback. It is only fair both to case managers and consumers – the two most important actors in this drama -- that these two levels of feedback exist and function routinely.

Health services research on HIV case management

As HIV case management matures as a source of care coordination and care connection, a range of topics needing research becomes clear. For example,

- Does formal professional education make for better case managers or do non-professionals provide quality case management?
- Is there a difference in sensitivity and cultural competence for case managers trained by consumers in consumer-designed training versus those that are only professionally trained?
- Is there a relationship between cultural competence and the sense of physical security experienced by consumers or case managers?
- Do HIV-positive case managers provide more service, better service, or more sensitive service?
- Are some models of supervision more effective than others (for instance, group supervision versus individual supervision)?
- Is training for active listening effective? For sensitivity training? If so, what kinds of training work best? Who are our best trainers?
- How does consumer involvement in the hiring of case managers affect the attrition of case managers? Or consumer satisfaction with case management?

No one wants or needs the answers to these and other important questions more than consumers and the case managers who work together with them. Because this relationship is critical, because poor case management is

dangerous, because so much care for so many people depends on case management, answering these questions must be a priority of the HIV care system.

Conclusion

Case management is the paradigmatic, quintessential feedback loop. It is hard to imagine a service more dependent on current, accurate information and on effective communication. Yet the possibilities for miscommunication and misunderstanding abound. In preparing and supporting case managers, every means of support and education available should be employed to minimize these possibilities and to quickly diagnose and remedy any resulting problem.

We can best support case managers by recognizing the complexity of their responsibilities and of their clients' lives and by working to set standards for education and training that clarify expectations: expectations they have for themselves, that clients have of them, and that the organizations they work for have of them. These standards can be broadly defined in ways that are responsive to various models and locations.

No matter where or what model, the existence of five elements (the person infected or affected by HIV, the *case* manager, their *interactive field*, their *service environment*, and their context) must not be ignored. These standards can be enforced and evaluated only after they have been defined for the particular location. Every case manager, however, needs access to the information, training, and supervision delineated here. As we know from the example of case management, implementing a plan challenges us more than planning itself. In our planning for effective case management, we need to provide the necessary resources – funding and technical assistance, for example – to ensure that our plans become realities.

HIV case managers work in variety of settings and in geographic locations that range from the most rural to urban epicenters. Designing training, creating standards, and developing evaluation tools will depend on the setting and the model. However, we now know the elements that must be included. Managers and funders have a legitimate role in establishing these elements. To be effective, however, the processes used in establishing these frameworks should include collaboration with the system's most critical components – consumers and case managers.

References

- Austin, Michael. "Monitoring Worker Performance" in *Supervisory Management for the Human Services*, Prentice Hall, 1981, pp.199-227.
- Cheung, Kam-Fong Monit, et al. "Company Based Evaluation of Case Management Skills in Child Sexual Abuse Intervention," *Child Welfare*. Vol. LXX, No.4, July - August 1991, pp. 425-435.
- Girard, et al. Case Management Sub-Committee Report, HIV/AIDS Regional Plan, The Philadelphia AIDS Consortium, September 1991.
- Grier, Jan, RN. Standards and Evaluation in Community Based Case Management, *JANAC* Vol. 4, No.1, January-March, 1993, pp. 32-33.
- Macro International Inc., Community Services Workstation Network Participant Manual "Collaborative Team Case Management," Appendix 2, pp. A2-1-5.
- Ibid. "A Model of Case Management: Toward Empirically Based Practice," pp. A2-6-34.
- Socialwork Speaks; NASW Policy Statements, "Case Management in Health Education, and Human Service Settings," NASW, 1991.
- Wright, Janice, M.S., RN, et al. "Evaluation of Community Based Nurse Care" Management Activities for Symptomatic HIV/AIDS Clients, *JANAC* Vol. 4, No.2, April-June 1993, pp. 37-47.

Appendix **Development of an Acuity Assessment for HIV Case Management**

ActionAIDS, Inc., a non-profit AIDS service organization in Philadelphia, has developed and implemented an acuity assessment **mechanism**.⁸ This appendix discusses how the mechanism was developed and implemented.

The assessment weighs the client needs based on needs and risks. “Needs” are the practical and psychosocial issues and problems affecting a client’s life, such as medical status, psychological stability of the family, and concrete life management needs such as income and housing. “Risks” are the psychological and environmental barriers that impact on client needs. They include such things as involvement in the care plan, support systems, and whether or not the caregiver in the family is sick.

Briefly, six factors are each given a weight from one to five. These are totaled to determine the “total acuity” for each case, which ranges from 6-30. Each case manager’s caseload is totaled. New cases are assigned to the case managers with the lowest acuity totals. The process helps prevent any one case manager from having a disproportionate number of high-acuity cases. The process has ultimately lead to a more consistent quality of service to each client. It also supports the case manager’s ability to more quickly reassess clients and provide more proactive support to clients as needs and risks change.

As the HIV epidemic continues to escalate, and the fiscal constraints increase, **ActionAIDS** continues to identify ways to improve the efficiency of its resources, ultimately allowing it to provide high quality services to more clients. This acuity process, implemented in May 1995, has been successful in improving the agency’s case management efficiency and quality of service.

Concept

Traditionally, case managers in social service agencies are expected to carry a specific number of cases. As a case is closed, for whatever reason, another is

⁸ **ActionAIDS** would like to acknowledge that this project was made possible, in part, through the funding of a grant by the Special Projects of National Significance, Bureau of Health Resources Development, Health Resources and Services Administration. **ActionAIDS**, Inc. is located at 1216 Arch Street, 6th floor, Philadelphia, PA 19107, tel: (215) 981-0088. The author served as executive director from 1987-1996.

assigned. Historically, all case managers in an agency carried about the same number of cases. HIV case management followed this practice.

Through research and the development of new drugs, HIV-infected individuals are living longer. This positive change has influenced the case management process in two major ways. First, clients are in the case management process for a longer period of time, which has allowed cases to achieve increased stability. Second, clients seeking HIV case management more frequently present with multiple disabilities and multiple diagnoses. We have begun serving more clients and families with more physical disabilities as well as substance addiction, abuse issues, and mental or emotional disabilities.

Over time, a significant inequity developed among the workloads of case managers, even though they all had the same number of clients. Caseloads that consisted primarily of new cases (as with the addition of positions) were typically more time intensive than older more stable caseloads.

It became clear that a new method for assigning cases needed to be created. As there was none in the social services industry, we began looking to other service industries for a model.

In November **1994**, ActionAIDS decided to adopt an acuity-based mechanism (based on hospital models) as a method of assigning and evaluating client cases. In the hospital model, the acuity process identified specific nursing care activities for each patient. Each activity was assigned a numeric weight. This resulted in a number that estimated the amount of nursing care each patient would need over a period of time. Nursing managers then transferred the total unit figures into allocation of staff. Many studies have demonstrated that, in addition to improving staff efficiency, the acuity process balances workloads, and ultimately allows for improved quality of care and reduced staff turnover due to burnout.

Goals

In order to customize a model for our service, we needed clearly defined goals. In developing the acuity mechanism, we identified the following goals:

- . Improving consistency and quality of service to all clients.
- . Designing a process that would only take minutes to complete.

CHALLENGE AND RESPONSIBILITY OF CASE MANAGERS

- Creating a finished product to assist the case managers in more quickly developing an individualized and meaningful care plan as client needs changed.
- . Bringing about equity in the actual workload shared among case managers.
- . Increasing the service capabilities of the direct services unit through improved time management for case managers, coordinators, and upper management.

Key Definitions

Client: The HIV-symptomatic or AIDS-diagnosed individual for whom case management services were initiated.

Family Unit : All individuals, living under the same roof with the client, and sharing resources to maintain a household.

Primary Caregiver : The individual that most frequently assumes responsibility for the well-being of the family unit.

Disruption: Situations or behaviors that create stress and/or chaos within the family unit; these include abuse, changing or transitional family unit, unpredictable behavior of family members, and anxious or depressive behaviors.

Life Management: The ability to establish a reasonable standard of living; these include safe and adequate housing, adequate food, health care coverage, legal services, and transportation.

Tool development process

To meet the established goals, we identified assumptions from which we could work in developing a tool. The assumptions are as follows:

- Services to an individual *client are* not provided in isolation of *their family unit*.
- The time involved in providing case management services to any one client/family is significantly influenced by that client's or that family's vulnerability in a crisis situation.
- It is less time consuming to provide case management services to a *client/caregiver* who is involved in and committed to the case management

process than it is to provide case management services to a **client/caregiver** who is not.

- It is less time consuming to provide case management services to a **client/caregiver** who has a strong support system outside the case management process than to provide case management services to a **client/caregiver** who depends on case managers for primary support.
- It is less time consuming to provide services to a family unit when the *primary caregiver* is healthy (without a serious chronic physical or mental illness) than it is to provide services when the primary caregiver has a chronic illness.
- It is less time consuming to provide services to a family unit with fewer chronic illnesses than it is to one with many chronic illnesses.
- There is a direct relationship between a case manager's time spent on a client/family and the cumulative number and intensity of the physical health issues within the family unit.
- There is a direct relationship between a case manager's time spent on a client/family and the cumulative number and intensity of psychological or emotional *disruptions* within the family unit.
- There is a direct relationship between a case manager's time spent on a client/family and the cumulative number and intensity of *life management* issues within the family unit.

After completing the goals and assumptions, it became clear that the existing model of assessing **client's/family's** need for case management based solely on concrete needs was inadequate. The impact of risk factors significantly influenced the effectiveness and time spent on case management activities. For this reason, the tool was divided into two major categories of equal weight -- risk assessment and needs assessment. Both major categories contain three sub-categories, which are identified below.

Risk Assessment

There were three areas of risk selected to evaluate the **client's/family's** ability to manage a life crisis. First, we assess the **client's/caregiver's involvement** with and *availability* to the case management process. The involvement and availability identify how early in a developing crisis the case manager is involved. The assessment is based on the **client's/caregiver's** historical behavior. Second, we evaluate the **client's/caregiver's support system** -- those

individuals and resources that are available and reliable for problem solving with clients and/or caregivers in the event of a crisis. Third, we identify the impact of *chronic illness* on the family unit. The health of the caregiver is most significant to the well-being of the family unit in a crisis. The number of chronically ill individuals within the family unit also is factored in as an additional vulnerability indicator.

Needs Assessment

The assessment of a client's needs provides a quantitative picture of the concrete situation of the family unit. The first area of evaluation is the *medical needs and health status* of the family unit. The acuity tool looks at indicators such as frequency of clinic visits, amount of assistance needed in performing activities of daily living, and nutritional issues. We also quantify factors such as medical compliance as a predictor of the amount of case management time that is required in attempting to improve compliance to stabilize the client's medical conditions.

The second area of evaluation is the *psychological stability* of the family unit. Again, we evaluate behavioral and more concrete issues. Behavioral issues, such as the frequency of disruption and chaos within the household, for whatever reason, are quantified. For the purpose of this assessment, the reason for the behavior (drug and alcohol use, mental health, abuse) is less important than how the family unit, and ultimately the client, is affected by it. The fact that someone in the household had a substance addiction does not, in and of itself, mean substance addiction is disruptive to the family unit. The acuity tool quantifies the frequency and severity of abusive or neglectful behavior within a family unit, rather than the degree of addiction. We know that the frequency and severity of disruption and chaos (negative and positive) are factors that influence the time a case manager spends on the case.

The final area of assessment is *social stability, or concrete life management needs*. This includes the status and urgency for medical assistance, housing, food, utilities, safety, and transportation. We also quantify the cumulative effect of these needs. More case management time must be allocated to cases in which the client has more numerous needs.

Implementation and Findings

In January 1995, the tool was completed and piloted by 33 percent (4) of the case managers in one department. Revisions were made and the pilot was completed in April 1995. In May, a group-training was completed for all case managers and supervisors in our largest service department. The entire client base in this department was evaluated using the tool. To ensure reliability of

data and to support training, the initial caseload assessment for each case manager was completed with the supervisor and the acuity project coordinator. The initial assessment process typically took about 2 hours for each case manager to complete.

The assessment was repeated every 2 weeks (individual assistance was provided as needed). A worksheet listing each client's ratings (from high to low) was reviewed by case managers and coordinators. This served as a common point of communication when discussing clients in supervision. This process has stimulated client specific and general discussions between the case manager and the supervisor relating to service care plans, problem solving, priority setting, and time management.

The same month, the intake process was revised to include an acuity rating for all pending clients. Until this process was initiated, assessing the intensity of need for new clients was more subjective. Completing the acuity assessment at the intake stage assists in more accurate and appropriate assignment of clients.

The results of the initial findings, looking at *total acuity*, revealed a wide range among individual caseloads, from 608-818 (see table below). The spread among caseloads, from high to low, was 26 percent. At that time the average client acuity for the entire client base was 16.6.

May 1995 Findings	Standard Case Management	Waiting List
<i>Number of clients</i>	513	24
Case manager FTEs	12.5	NA
Average caseload	41	NA
Acuity range among case managers	608-818 26% spread	478
Average client acuity	16.6	19.9

After comparing individual caseloads, we further developed the process to include individual client ratings that would reflect the amount of case management time needed for client-specific services. Clients with acuity totals of 20-30 were considered *intensive*. Clients with totals of 14-19 were considered *moderate*. Clients with totals of 6-13 were considered *stable*.

The total acuity numbers correlated directly with the perceived manageability of workloads by individual case managers. In other words, those case managers with the highest acuity totals felt most overwhelmed by

their workload (the data collection process increased the reliability of case manager perceptions). Those with the lowest acuity totals felt their workload to be more easily managed. At that time, each case manager in the test department had 39 to 42 cases.

In June 1995, the agency began assigning new clients to case managers based on the acuity system. Case managers with the lowest acuity totals were assigned new clients. In August 1995, a review of the impact the acuity mechanism on case manager work loads was performed. The staff identified the following positive outcomes:

- Case managers whose total acuity had lowered since May 1995 felt their workload was more manageable.
- Case managers felt that the tool accurately reflected (80 to 90 percent of the time) the actual amount of time spent on cases.
- Case managers whose total acuity in August was higher than it had been in May, felt somewhat more challenged by their workload in August.
- There was a universal “sense” of greater equity among workloads.
- More cases were closed than in the past as a result of identifying clients/families with a long history of non-adherence to the service care plan.

Issues raised regarding the process included:

- The frequency of client change did not support completing the process every 2 weeks. Monthly assessments to determine client changes were suggested.
- The case managers reported a discrepancy between the amount of time spent and acuity totals for some clients at the top and bottom of the scale. They discussed ways to change the tool and assess how the results were interpreted. They decided to give the process three additional months before any changes would be made.
- The tool did not account for the time spent on the “over consumer,” the individual that repeatedly contacts case managers to update or repeat discussions related to his or her case. This was determined to be more of a “limit setting” issue and would be handled in supervision.

The results below were shared with staff as part of the review process. Comparing May 1995 and August 1995 results shows that the spread among case managers dropped from 26 percent to 15 percent. The average clients per full-time equivalent (FTE) increased from **41** to **42** clients. The average client acuity increased from 16.6 to 17.2. We determined that this increase

was the result of closing cases in which service provision was compromised due to client adherence and commitment failures. The act of closing cases reduced the waiting list, and the intensity on the waiting list dropped.

August 1995 Findings	Standard Case Management	Waiting List
<i>Number of clients</i>	526	184
Case manager FTEs	12.5	NA
Average caseload	42.1	NA
Acuity range among case managers	702-854 15% spread	341
Average client acuity	17.2	18.9

Following the August **1995** review, the acuity assessment was reduced to a monthly process. It continues to be utilized as described above.

In addition, coordinators and directors utilize an Acuity Summary Sheet (which compares all case managers' total caseloads), along with other management tools. This facilitates discussion of future staffing needs, options related to the waiting list, and case management practices relating to quality of service. As a result, the management team can more quickly respond to staff overload or underutilization.

Another analysis, conducted in October 1995, demonstrates a continuing trend consistent with many of the initial goals. The assessment process now takes each case manager only 10-15 minutes to complete. The case managers report that the worksheet facilitates more effective and efficient updating of individual client services care plans because it keeps them focused on changing situations. There is more equity in case managers' workloads as demonstrated by:

- the case managers' self-reporting,
- more consistent, timely completion of administrative duties, as reported by supervisors,
- a more even distribution among case managers in reporting complex or crisis situations to supervisors.
- finally, the agency has increased its service capability per case manager FTE, from **41** clients in May 1995 to 44 clients in October 1995.

Increased efficiency and a focus on closing cases in which the client demonstrates a lack of commitment or involvement allowed the agency to significantly reduce its waiting list by late October 1995.

October 1995 Findings	Standard Case Management	Waiting List
<i>Number of clients</i>	551	5
Case manager FTEs	12.5	NA
Average caseload	44	NA
Acuity range among case managers	750-818 8% spread	97
Average client acuity	18.5	19.4

In summary, the development of the acuity mechanism has been highlighted to this agency. The organization will continue to commit resources to improving and refining the process to include all of the service departments.

Next steps

- Staff have recognized that from 10 to 20 percent of the time, the amount of time spent with a client and the total acuity do not match. Through client-by-client analysis, staff found that the weighting for risk should be lower than for needs. The exact weighting will be determined when further data analysis is complete.
- A work group has been established to set standards or protocols of service for case managers related to acuity ratings. The standards will set a level of service expected from each case manager. In addition, they will set the level of service required for each client based on acuity classification (intense to stable).
- Complete the comparative analysis of actual time spent on an activity (using computerized daily logs) for a particular client and the client's acuity assessment. This will give further validity to the acuity process and identify practice issues that need improvement.
- Adapt the acuity tool as necessary in order to incorporate additional services **ActionAIDS** currently provides for specific populations or distinct client needs; these include the family program, prison program, hearing impairment services, transgendered services, housing services, and pastoral counseling.



U.S. Department of Health and Human Services
Health Resources and Services Administration
HIV/AIDS Bureau
Office of Science and Epidemiology